Public Health Devon

Devon County Council

DEMENTIA
HEALTH NEEDS ASSESSMENT
FOR DEVON
September 2014

Contents

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1.0 Introduction

1.1 The aim of this Health Needs Assessment is to provide an overview of dementia by understanding the risk factors, the population and projected growth in Devon to help inform future service provision.

1.2 Dementia is a priority for the Devon Health and Wellbeing Board in the Joint Health and Wellbeing Strategy.

1.3 The Health Needs Assessment was undertaken in response to a gap in intelligence regarding dementia in Devon.

1.4 The Dementia Evidence Review is provided as a supplement to this report and summarises dementia services in primary care, secondary care, End of life care and social care.

2.0 Background

2.1 In the UK, there are approximately 800,000 people with dementia (1.3% of the population). This is estimated to rise to 1 million in 2021 and 1.7 million by 2051. Dementia is most common in older people and one in 14 people over 65 years have a form of dementia. This increases to one in six people for people over 80 years old.

2.2 The increasing prevalence of dementia suggests that more people with dementia may experience severe stages of the disease in the future.

2.3 It is estimated that a third of people with dementia live in a care home (nursing or residential home). Of those living in a nursing home, 64% of people have some form of dementia.

2.4 Figures from dementia 2012 report estimate that dementia costs £24 billion a year including NHS costs, social care costs, accommodation costs and informal care costs. This is a 41% increase from £17 billion estimated in 2007.

2.5 The most common types of dementia are Alzheimer's (62%) and vascular dementia (17%).

2.6 People with dementia experience declining function including memory, communication and daily activities such as cooking or dressing.
Psychological symptoms can include agitation, depression, psychosis, shouting and aggression.[1]

2.7 There are several key documents on dementia including the NICE dementia in 2006, the Department of Health *Living well with dementia: A National Dementia Strategy* (February 2009) which was joint guidance by NICE and the Social Care Institute for Excellence.

[1] NICE contributes to the National Dementia Strategy.
http://www.nice.org.uk/newsroom/guidanceinfocus/infocusdementiastrategy.jsp (accessed 20.10.2012).

2.8 In addition, the quality outcomes guidelines (September 2010) for people with dementia prioritised; early diagnosis and intervention, living well with dementia in care homes and reducing the use of antipsychotic drugs.
The report 'Common and complex: Commissioning effective dementia services in the new world' by the Alzheimer's society (December 2011) also made recommendations on addressing challenges of dementia commissioning.

2.9 These guidelines and recommendations are not discussed in detail in this report since they are already being applied in Devon for dementia care.
Their summaries are provided in Appendix 1.

2.10 The above guidelines and recommendations have contributed to a 28% improvement in dementia recording from GP practices nationally (since 2006/07).

2.11 Prescribing patterns for anti-psychotics have reduced from 17% to 7% for current use and from 14% to 4% for newly prescribed drugs. The highest prescribing region was the North West of England at 13%. Devon's prescribing was 6% and the lowest prescribing region was London at 2%.

2.12 Regarding evidence, a broad literature review was undertaken on dementia services from primary care, secondary care, end of life care and social care. The Dementia Evidence Review is provided as a supplementary report with summaries included in the relevant sections in this Health Needs Assessment.

2.13 Overall, the Dementia Evidence Review found a paucity of evidence on dementia services with many studies being of low quality.

2.14 Only a few UK studies were found and evidence on service models were conducted in urban settings which may be less favourable in the rural setting like Devon.

2.15 The few studies conducted in rural areas highlighted the additional challenges faced including shortages of skilled staff, reduced access to services due to lack of transport compared with urban services.

3.0 Dementia and Risk Factors

3.1 Dementia causes damage to the brain resulting in a progressive decline function, including memory, reasoning, communication skills and the skills needed to carry out daily activities.

3.2 Dementia is categorised as mild, moderate or severe and are characterised as follows;[2]

- Mild dementia includes impaired attention and memory, short term memory loss, occasional confusion, coping with daily activities and living independently but with assistance.

[2] http://www.birmingham.ac.uk/Documents/collegemds/haps/projects/HCNA/HCNAVol2chap14sh5L.pdf (accessed 16.1.14).

- Moderate dementia includes recent amnesia, disorientation in time and place, poor reasoning and understanding of events, requiring some help with personal care and daily routine.

- Severe dementia includes incoherent speech, inability to recognise close relatives, incontinence and dependence on personal care services.

- Later symptoms such as aggression, disorientation are associated with the illness rather than being part of the prognosis.

3.3 Dementia is a late onset condition affecting people aged 65 years and older. Two-thirds (68%) of all people with dementia are 80 years and older, and one sixth (17%) are 90 years or older. The life expectancy for people with dementia is on average seven to 12 years after diagnosis.

3.4 There a number of risk factors associated with dementia. Genetic risk factors most commonly associated with dementia are Alzheimer's disease, Pick's disease, Huntington's disease fronto-temporal dementia.[3]

3.5 Mild Cognitive Impairment[4], stroke, depression or schizophrenia[5] are also associated with dementia.

3.6 Regarding vascular risk factors type 2 diabetes, hypertension, obesity and dyslipidaemia are also associated with increased risk of dementia.[6]

3.7 There was however inconclusive evidence whether exercise[7] [8] [9], a Mediterranean diet or vegetable consumption is protective against dementia.[10] Diet and physical activity will impact on obesity which is a risk factor.

[3] Plassman BL, Williams Jr JW, et al. Systematic review: factors associated with risk for and possible prevention of cognitive decline in later life Annals of Internal Medicine (2010) 153; 182-193).

[4] Mitchell AJ, Shiri-Feshki M. Rate of progression of mild cognitive impairment to dementia – meta-analysis of 41 robust inception cohort studies Acta psychiatrica Scandinavica 2009 119(4) 252.

[5] Cooper B, Holmes C. Previous psychiatric history as a risk factor for late-life dementia: a population based case-control study Age & Ageing 1998 27(2); 181-188.

[6] Kloppenborg RP, van den Berg E, et al. Diabetes and other vascular risk factors for dementia: Which factor matters most? A systematic review European Journal of Pharmacology 585 (2008) 97-108.

[7] Ahlskog JE, Geda YE, et al. Physical Exercise as a preventative or disease-modifying treatment of dementia and brain aging (2011) Mayo Clin Proc. 86(9): 876-884.

[8] G Morgan, J Gallacher et al. Physical activity in middle-age and dementia in later life: findings from a prospective cohort of men in Caerphilly, South Wales and a Meta-Analysis by JAD Volume 31/Issue 3 (August 2012).

[9] Cadar D, Pikhart H et al. The role of lifestyle behaviours on 20-year cognitive decline Journal of Aging Research 2012.

[10] Loef M, Walach H. Fruit Vegetables and prevention of cognitive decline or dementia: a systematic review of cohort studies Journal of Nutrition (2012) 16(7); 626-630.

4.0 Devon Summary

4.1 Devon has a large elderly population compared to the England average. Certain areas such as Budleigh Salterton have been estimated to be 20 years ahead of the demographics, with the highest percentage of people over the age of 85 years. A consequence of this is a larger elderly population living in residential and nursing homes.[11] *12*

4.2 Approximately 24% of Devon's population in 2012 were 65 years and older (178,300 / 756,300) and this will increase to 253,300 in 2030. Those aged 85 years and older represent 3.5% of the Devon population. This is currently 25,700 and will increase to 48,900 in 2030.[13]

4.3 In 2012, there were 13,312 people estimated to have dementia in Devon which is 1% of the total Devon population; of which 215 have early onset dementia. By 2030, the numbers of people with early onset dementia is predicted to remain stable, but there will be a steep increase for late onset dementia increasing to 21,858 by 2030.

4.4 Devon sees approximately 1,882 new cases of late onset dementia annually. The proportion of people with dementia in Devon districts was higher (1.75%) than the South West region (1.51%) and England (1.23%) in 2012.
East Devon district had the highest proportion of people with expected dementia at 2.35% and Exeter district the lowest at 1.28% in 2012.

4.5 Approximately 42% of the population with dementia in Devon are recorded on GP registers compared with 48% England in 2013. These estimates are based on the Dementia UK, 2007 Report based on a consensus exercise with experts and does not account for risk factors.

4.6 Regarding social care, 77% of mental health assessments in older people are estimated to be from people with dementia in Devon, compared with 48% in the South West and 52% in England.

4.7 The total annual cost to Devon of people with dementia is estimated to be £333.6 million currently and is expected to increase to £556.8 million by 2030.

4.8 Summaries of dementia care achievements in Devon are presented in Figure 1. They show that Devon has made good progress to improve dementia care. Current services being provided in Devon include memory clinics, complex care teams, day services, dementia carer's support, peer support, mentoring and the Alzheimer's Society Dementia Support Service.

4.9 Local stakeholder views from dementia carers showed that they wanted the current support to continue and better coordination between organisations regarding the information they provided.

[11] Health Care Quality for an active later life, Improving quality of prevention and treatment through information: England 2005 to 2012 May 2012. Peninsula College of Medicine and Dentistry Ageing Research Group for Age UK http://clahrc-peninsula.nihr.ac.uk/includes/site/files/files/10%20Review%20Care%20Home%20PB%20FINAL.pdf (accessed 1.11.2012).

[12] Annual public health report 2010/2011 Older people, Devon County Council / NHS Devon.

[13] http://www.poppi.org.uk/index.php?pageNo=315&PHPSESSID=c8tmlkc556blmjpupdnlcvjjv2&sc=1&loc=8254&np=1 (accessed 8.2.13).

The local commissioners and provider representatives felt that it was important to strengthen the current care pathway.

4.10 All views were being addressed through the Pan Devon Dementia Steering group and Older People Mental Health working group and the latest Dementia Strategy.

4.11 Devon's Dementia Strategy for 2013 to 2015 is prioritising; raising awareness, early diagnosis and supporting people to live well with dementia shown in Figure 2 below. There was evidence found to support memory clinics, end of life care and providing supportive services for people with dementia and their carers.

4.12 The limitations of this Health Needs Assessment included using data that was in the public domain especially if accessing local data was not feasible. In addition, a small sample of carers instead of people with dementia responded to the stakeholder feedback to provide a local context. So their views should be seen in the wider context of engaging service users.

4.13 Minority ethnic groups and learning disabilities and lesbian, gay, bisexual and transgender (LGBT) communities need consideration in future planning of dementia care

Figure 1: Devon achievements so far in providing dementia care

Devon wide

- An integrated dementia care pathway supported by the Dementia Roadmap http://dementiaroadmap.info/
- A programme of primary care GP education about dementia
- A steady rise in diagnosis rates
- Redesigned specialist NHS services to deliver a consistent Memory Service Model across Devon & Torbay
- Peer review and dementia care standards established in general and community hospitals
- Liaison services in acute hospitals
- Dementia friendly communities in Plymouth, Torbay, Tavistock and the Yealm parishes, with more in the pipeline, including Sidmouth, Crediton, Winkleigh and others
- Reduced antipsychotic prescribing
- Alzheimer's Society Dementia Support and Adviser service in all areas

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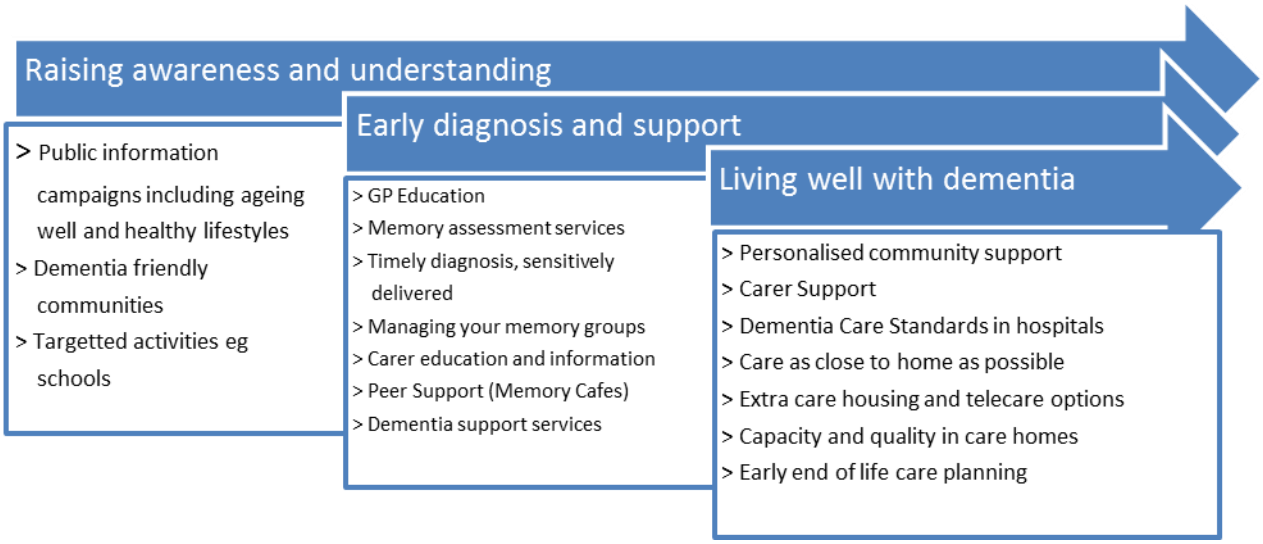
- Devon Dementia Care and Support Partnership with independent, statutory, voluntary and community sector partners
- 38 peer support Memory Cafes
- Devon Carers Centre reaching more carers
- Extra care housing developments inclusive of people with dementia
- Independent sector care home Kite Mark peer review pilot
- Intergenerational projects with 7 schools as part of a national pilot
- Library Memory Groups for people with memory loss and their carers
- A Devon Card to help families have Direct Payment

Figure 2: Updated Dementia Strategy for Devon 2013 to 2015



Estimating dementia severity, incidence and prevalence and future projections

4.14 Projecting Older People Population Information System (POPPI) and Projecting Adult Needs and Service Information (PANSI) produced by the Institute for Public Care and Oxford Brooks University[14] were used in this report to estimate current and future projected growth of dementia in Devon. This is because they are more recent than those used in the Alzheimer's Society, Dementia UK, 2007 report[15] and were derived from the Office for National Statistics dataset. The national estimates of prevalence and incidence rates of dementia were derived from Dementia UK, 2007 report as well as obtaining local data from the Public Health Intelligence team. The Dementia UK, 2007 report prevalence is based on expert opinion rather than reported prevalence and do not consider local variation or account for dementia risk factors such as age and gender. A recent study based on the Dementia UK, 2007 report studies adjusted for risk factors and found that the national prevalence of dementia should be lower than the current estimates.[16]

4.15 Other sources of estimating dementia prevalence include the Quality Outcomes Framework (QOF) dementia register estimates which are discussed in the Primary care section of this report. Additionally, estimating the demand for dementia services can be derived from Social care provision to older people with mental health, community mental health and crisis support services. The National Adult Social Care Intelligence Service (NASCIS) also provide estimates of the proportion of people with dementia in Nursing or Residential care. Given the varying dementia estimates from different data sources, this report uses information from the Dementia UK, 2007 report (as is current practice from other regions with dementia health needs assessments) as well as modelling from regional and national reports.

[14] http://www.poppi.org.uk/index.php?pageNo=334&loc=&mapOff=1 (accessed 20.1.13).

[15] Alzheimer's Society. Dementia UK. The full report, 2007.

[16] Matthews, F.E et al. 'A two-decade comparison of prevalence of dementia in individuals aged 65 years and older from three geographical areas of England: results of the Cognitive Function and Ageing Study I and II' The Lancet 2013; 382: 1405-12.

5.0 Dementia Characteristics – Types and Severity

Types

5.1 The most common type of dementia is Alzheimer's disease 62%, followed by vascular dementia 17%. Dementia can be related to other conditions as well such as vascular problems and Parkinson's disease. The cost of dementia is substantial and the direct costs of Alzheimer's disease alone are estimated to exceed the total cost of stroke, cancer and heart disease.[17]

5.2 Analysing data types of dementia is important as dementia is a syndrome with varying behaviour characteristics and disease progression. People with different types of dementia can have different needs because brain deterioration can occur without cognitive impairment.

Table 1: Types of dementia in Devon 2012 (based on Alzheimer's Society, Dementia in the UK, Report 2007)

Type of dementia	Proportion	Devon estimated numbers
Alzheimer's disease	63%	8,120
Vascular dementia	17%	2,227
Mixed (AD and VD)	10%	1,310
Lewy body Dementia	4%	524
Fronto-temporal dementia	2%	262
Parkinson's dementia	2%	262
Other	3%	392
Total	100%	13,097

5.3 Table 1 shows Devon estimates of Dementia in 2012 based on the Alzheimers UK, 2007 report. Alzheimer's disease followed by vascular dementia or the combination of both are the most common types representing 90% of dementia.
The local picture in Devon indicates that almost 50% of people with dementia have mixed dementia.

5.4 Minor causes of dementia such as fronto-temporal are due to changes in the front part of the brain. Parkinson's disease is due underlying neurological illness and Lewy body dementia can cause hallucinations and delusions. Alzheimer's Disease has a more gradual onset with disability and dependence becoming more prominent later on in life.

5.5 Vascular dementia is more common among Asian and Black Caribbean communities because increased risk from cardiovascular disease, hypertension and diabetes.

[17] Spotlight on Dementia, A Health Foundation Improvement Report. The Health Foundation. http://www.health.org.uk/public/cms/75/76/4181/2703/Spotlight_Dementia%20Care.pdf?realName=55ojeV.pdf (accessed 4.10.13).

Severity

5.6 A German study estimated for moderate dementia, the societal cost was 70% higher than for mild dementia. Formal health care services costs for moderate dementia were 14.3% higher than for mild dementia.[18]

Table 2: Percentage of people with late onset dementia; mild, moderate and severe by age in Devon (based on Alzheimer's Society, Dementia in the UK, Report 2007)

Age (years)	Mild %	Moderate	Severe
65-69	62%	32%	6%
70-74	63%	30%	7%
75-79	57%	31%	12%
80-84	57%	32%	11%
85-89	54%	33%	13%
90-94	49%	33%	18%
95+	42%	35%	23%
Average % (Devon numbers)	**55.0% (7,203)**	**32.2% (4,217)**	**12.8% (1,676)**

5.7 Table 2 shows that for late onset dementia in the Devon; 55% (7,203) of people have mild dementia, 32% (4,217) have moderate dementia and 13% (1,676) have severe dementia (ranging from 6% to 23%). The severity increases with age as the disease progresses and indicates the potential level of care needed.

5.8 Approximately two thirds of people estimated to have mild dementia can function independently in the community. Services therefore should recognise the variation in dementia and changing need requirements from mild to severe stages of the disease.

5.9 In addition, since age is a major risk factor for dementia it is important to consider the other preventable risk factors such as diabetes, high cholesterol, smoking and hypertension.

5.10 According to Health Intelligence data over the next 10 years. The prevalence in the population will increase for diabetes and cholesterol but reduce for smoking and hypertension which will impact on the dementia burden.

[18] Schwarzkopf L, Menn P et al. Costs of care for dementia patients in community setting: an analysis for mild and moderate disease stage. Value Health. 2011 Sep-Oct;14(6):827-35. Epub 2011 Jun 25.

6.0 Early Onset Dementia

6.1 There doesn't seem to be major differences in demographics and background between people with early and late onset dementia.[19]

6.2 Approximately 2.5% of people with dementia are estimated to have early-onset dementia occurring before the age of 65 years. Early onset dementia is mainly due to multiple sclerosis, motor neurone disease, Parkinson's disease, Huntington's disease or alcohol related disease.[20] People with learning disabilities and minority ethnic groups are also at a higher risk of developing early onset dementia.[3]

6.3 Projections in Table 3 and Figure 3 show that early onset dementia will be stable in Devon over the next 20 years. Is it estimated that there were 215 people with early onset dementia in 2012 and there will be 216 in 2030.

Table 3: Prevalence of early onset dementia in the UK by age and sex (based on Alzheimer's Society, Dementia in the UK, Report 2007)

Age (years)	Men (per 100,000)	Women (per 100,000)	Total (per 100,000)
30-34	8.9	9.5	18.4
35-39	6.3	9.3	15.6
40-44	8.1	19.6	27.7
45-49	31.8	27.3	59.1
50-54	62.7	55.1	117.8
55-59	179.5	97.1	276.6
60-64	198.9	118.0	316.9

6.4 Table 3 also shows the estimates of dementia prevalence from the Alzheimer's Society Dementia UK, 2007 report and these figures are commonly used to estimate dementia in local regions. For early onset dementia, prevalence is higher in men than women and increases exponentially with increasing age in both groups.

6.5 PANSI (Projecting Adult Needs and Service Information) provides the population projections estimates for some diseases in populations less than 65 years old. Table 4 below, shows their estimated projections of early onset dementia in Devon.

[19] McMurtray A, Clark DG et al. Early-onset dementia: frequency and causes compared to late-onset dementia. Dement Geriatr Cogn Disord.2006;21(2):59-64. Epub 2005 Nov 4.

[20] Medical Research Council Cognitive Function and Ageing Study 2005.

Table 4: Numbers of early onset dementia in Devon from 2012 projections to 2030 (based on PANSI 2012 projections)[21]

	2012		2015		2020		2025		2030	
Age (years)	M	F	M	F	M	F	M	F	M	F
30-39	3	3	3	3	3	4	3	4	3	4
40-49	10	13	10	12	9	10	8	10	9	10
50-59	59	41	62	42	67	46	64	44	56	38
60-64	53	33	49	32	52	33	58	38	58	38
Total	**125**	**90**	**124**	**89**	**131**	**93**	**133**	**96**	**126**	**90**

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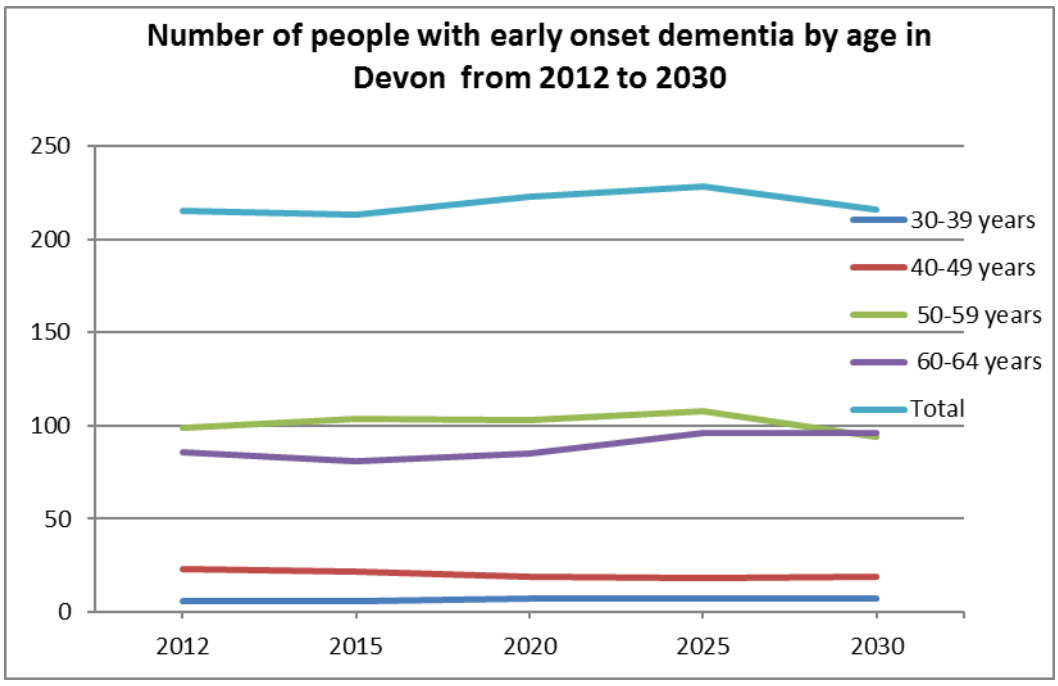
Figure 3: The number of people with early onset dementia projections from 2012 to 2030 (based on PANSI 2012)



6.6 Figure 3 is the graphical representation of PANSI estimates showing the number of people with early onset dementia by age group in Devon. The lowest numbers are in the 30 to 49 year age group and the highest in the 50 to 65 year age group.

[21] PANSI http://www.pansi.org.uk (accessed 20.2.13).

7.0 Incidence And Prevalence Of Late Onset Dementia In Devon

7.1 Late onset dementia is more commonly associated with diabetes, hypertension, obesity, smoking, stroke / transient ischaemic attacks (TIA) and vascular infarcts (resulting in vascular dementia).

Incidence

7.2 Newly diagnosed cases of late onset dementia annually are based on findings from the Medical Research Council Cognitive Function and Ageing Study.

7.3 Table 5 shows the sharp age gradient. Applying the average incidence rates to Devon's population in 2012 suggests that there were 1,887 new cases of late-onset dementia each year (24.1/1000 x 78,300 over 65 year olds). The incidence being higher in women than men (after 80 years old) and increasing exponentially by age group.

Table 5: Incidence (new cases each year) of late onset dementia in England and Wales by age and gender (based on Alzheimer's Society, Dementia in the UK, Report 2007 *and* NICE Costing Report (2006)

Age (Years)	Men (per 1000 person years)	Women (per 1000 person years)
65-69	6.9	6.3
70-74	14.5	6.1
75-79	14.2	14.8
80-84	17.0	31.2
85+	58.4	71.7

Prevalence

7.4 The estimates of type of dementia were derived from Dementia UK, 2007 Report with estimated prevalence from 2011 Census data.

Table 6: Prevalence (current cases) of late onset dementia in the UK by age and gender (based on Alzheimer's Society, Dementia UK, Report 2007)

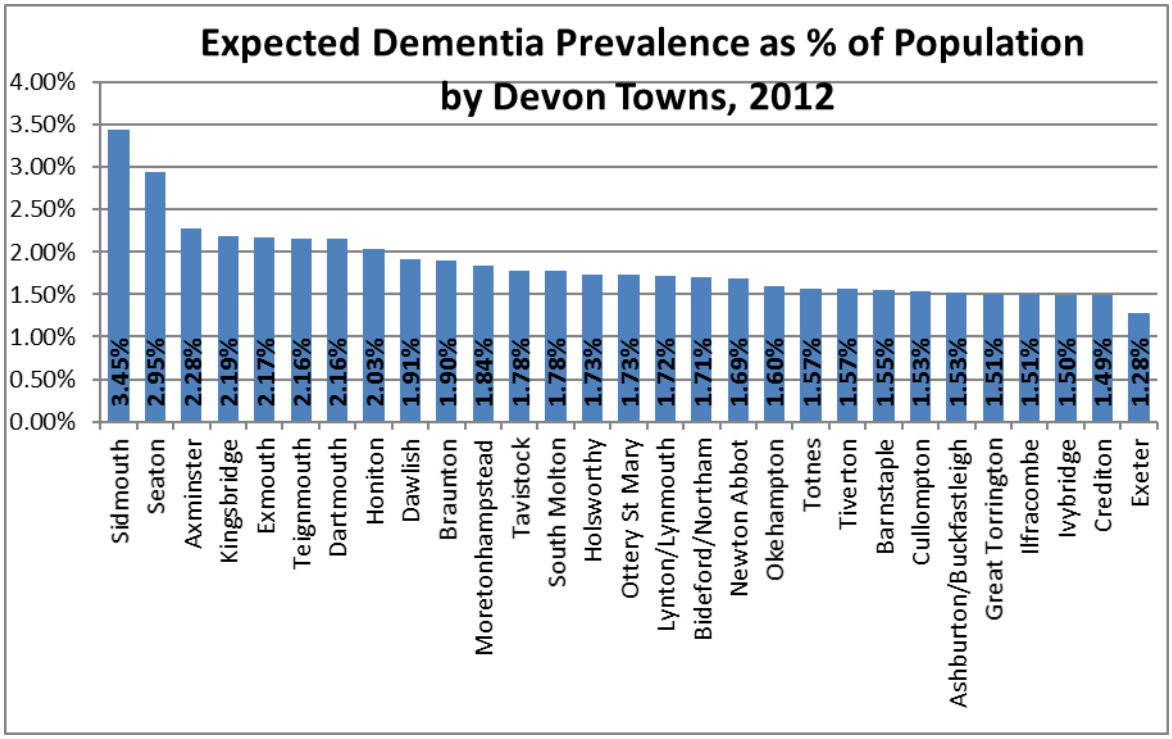
Age (years)	Men	Women	Total
65-69	1.5%	1.0%	1.3%
70-74	3.1%	2.4%	2.8%
75-79	5.1%	6.5%	5.8%
80-84	10.2%	13.3%	11.8%
85-89	16.7%	22.2%	19.5%
90-94	27.5%	29.6%	28.6%
95+	30.0%	34.4%	32.2%

7.5 Table 6 above shows that the estimated prevalence of late onset dementia from the Dementia UK, 2007 report increases exponentially. It is initially higher in men and becomes higher in women after 80 years of age. In 2012, there were 13,097 people over 65 years in Devon with late onset dementia.

7.6 Sidmouth town has the highest expected prevalence of dementia 3.45% and Exeter town the least at 1.28% (figure 4a and 4b below). The expected dementia prevalence also reflects the ageing pattern seen in Devon.

7.7 The Annual Public Health Report for 2010/11 for Devon also showed that Sidmouth town had the highest proportion of people aged 85 years and older at 8.1%.[5] Estimates suggest Sidmouth figures would be seen in the rest of England in 2076.

Figure 4a: The expected dementia prevalence in Devon towns, 2012 (combined data)[22]



7.8 Figure 4b below shows that in 2012, East Devon district had the highest expected prevalence of dementia 2.35% and Exeter district the least at 1.28%. The average expected dementia prevalence in Devon's districts is 1.70% compared with South West region average of 1.48% and England's average of 1.21%. Figure 4c shows the latest 2013 dementia estimates in the Peninsula region.

[22] Data source for expected prevalence charts: Alzheimer's Society, Dementia in the UK Report 2007; and Exeter System Resident and GP Registered Population Dataset, 2012.

7.9 Sidmouth town is in East Devon district and is likely to be contributing to the district's high prevalence of dementia compared with Exeter which had the lowest prevalence.

Figure 4b: The expected dementia prevalence in Devon districts, 2012 (combined data)

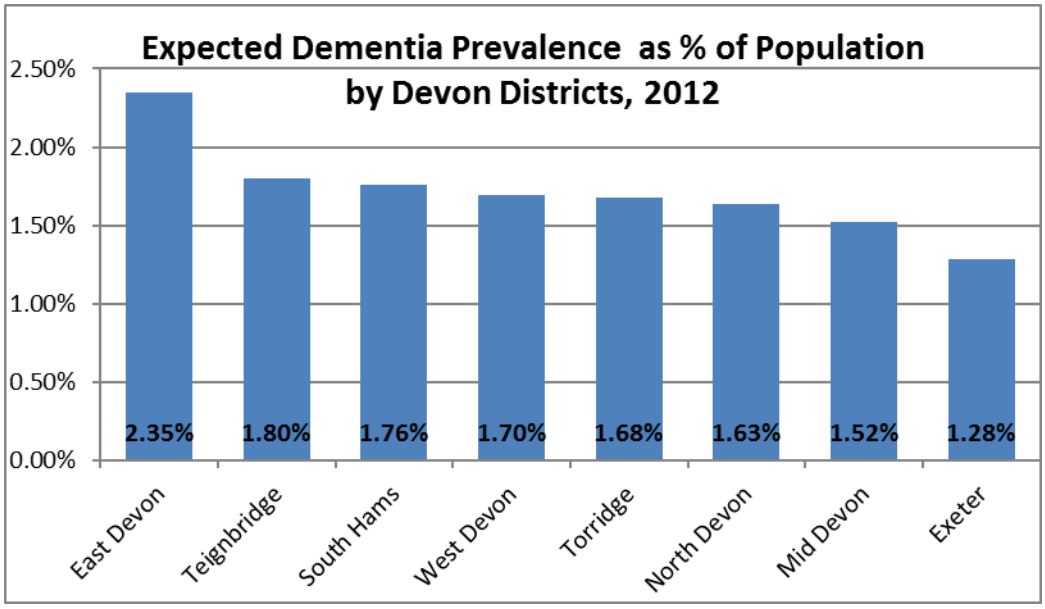
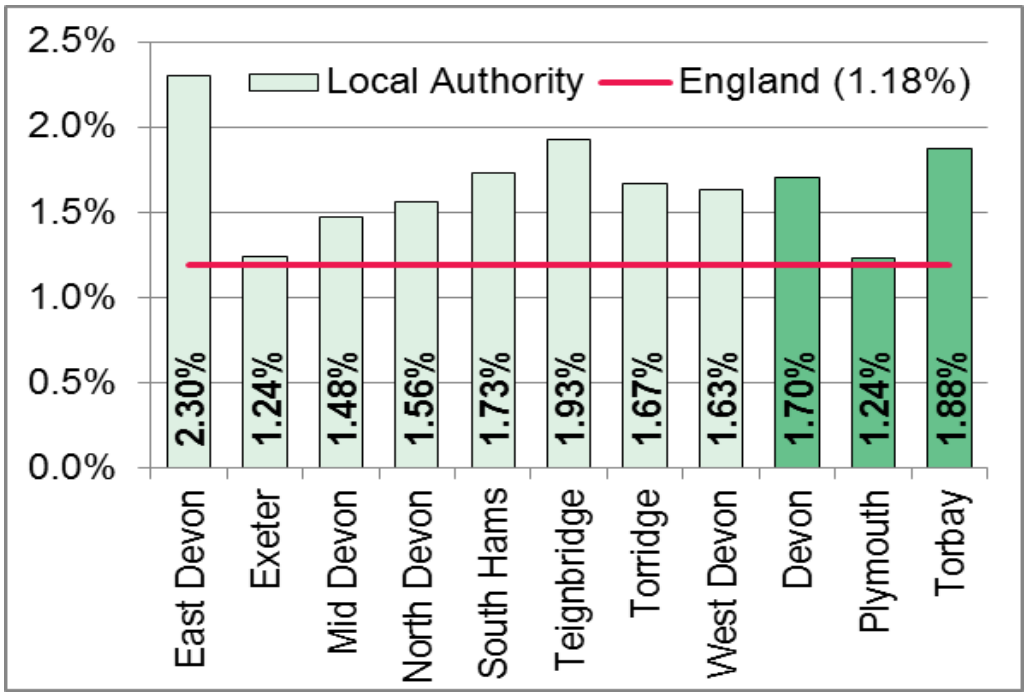


Figure 4c: The prevalence of dementia in Exeter districts and the Peninsula region, 2013. *(updated figures are a different dataset from 2012 figures 4a and 4b)*



7.10 Again, reflected in the ageing pattern Figure 4b and 4c shows that East Devon has the highest proportion of people with dementia. East Devon also

had the highest proportion of people 85 years and older 4.5% compared with the Devon average of 3.5 % and national average of 2.2%.

Table 7: Range of projected increases in percentage of people with dementia by Devon boroughs, 2012 to 2021 (based on POPPI projections)

Area	2012	2021	Percentage increase 2012 to 2021
West Devon	1.71%	2.08%	0.38%
Torridge	1.67%	2.02%	0.34%
Teignbridge	1.84%	2.18%	0.34%
South Hams	1.75%	2.07%	0.32%
North Devon	1.68%	2.00%	0.32%
Mid Devon	1.52%	1.80%	0.28%
East Devon	2.27%	2.53%	0.26%
Exeter	1.32%	1.50%	0.18%
Devon	1.75%	2.04%	0.29%
Plymouth UA	1.21%	1.41%	0.21%
Torbay UA	1.88%	2.24%	0.36%
England	1.23%	1.43%	0.20%
South West	1.51%	1.77%	0.26%

7.11 Table 7 above shows that all Devon districts will see an average of 0.29% increase in dementia by 2021.

8.0 Relevant Groups

Black, Asian and Minority Ethnic (BAME) Groups

8.1 Although dementia prevalence in BAME groups is currently small, a European study from 15 countries showed that they attended 69% of dementia clinics.[23] They may also require different management since hypertension and cardio vascular diseases are more common indicating higher levels of vascular dementia in the future.

8.2 The Dementia UK, 2007 report estimated that 1.7% (11,400) of people with dementia were from BAME groups (compared with 0.9% in Devon) and they experience higher levels of early onset dementia (6.1% compared with 2.2% in the White population).

[23] Nielsen TR, Vogel et al. Assessment of dementia in ethnic minority patients in Europe: a European Alzheimer's Disease Consortium survey. Int Psychogeriatr. 2011 Feb;23(1):86-95.

8.3 The Social Care Institute for Excellence reported that the highest proportion of older people from BAME groups were from Black Caribbean and Asian Indian backgrounds.

8.4 For late onset dementia in the UK, there were similar prevalence between White groups and BAME groups. However BAME groups were less likely to receive a diagnosis or received it at a later stage than White groups[24]. This highlights that equity in accessing dementia health care for BAME groups should be considered in Devon's dementia care pathway in the future.

8.5 A service evaluation in Bradford revealed that social stigma and a lack of awareness of dementia within the Asian community needed addressing. For example, there is no word for dementia in Asian languages. Supportive and easily understood information provided with awareness and education about dementia helped reduce the social stigma, where sufferers were labelled as 'mad'.[25] A similar project was conducted in the Greater Manchester area on 72 Chinese older people with dementia and their carers.[26]

Down's syndrome

8.6 For people with dementia, Down's syndrome is the most common learning disability found. NICE Social Quality Standards estimate that their longevity is rising. The dementia prevalence in people with Down's syndrome over 65 years was two to three times higher than those without a learning disability.[27]

8.7 PANSI / POPPI data estimated that in 2012, Devon had 272 people under 65 years with Down's syndrome and this will remain stable; with 271 people in 2020. There were six people 65 years old or older with Down's syndrome in 2012 and there will be eight in 2020.

8.8 Two literature reviews showed that people with Down's syndrome required multiple services including social care services.[28]

8.9 Another study showed that reducing marginalisation experienced by this group required staff training and future planning as well as addressing accommodation to reduce isolation.[29]

[24] Black and minority ethnic people with dementia and their access to support and services Research Briefing March 2011 Social Care Institute for Excellence.

[25] AZAM Nazia, Evaluation report of the Meri Yaadain dementia project. GIRLINGTON ADVICE AND TRAINING CENTRE Publisher: 2007 Pagination: 32p.

[26] CHAN Nancy, et al Publisher: National Institute for Mental Health in England: 2007 Pagination: 121p.

[27] www.leicester.gov.uk/EasySiteWeb/GatewayLink.aspx?alId=97701 (accessed July 2012)

[28] Llewellyn P. The needs of people with learning disabilities who develop dementia: a literature review Dementia: the International Journal of Social Research and Practice, 10(2), May 2011, pp.235-247.

[29] Watchman K. People with a learning disability and dementia: reducing marginalisation. Journal of Dementia Care, 20(5), September 2012, pp.34-38.

Lesbian, Gay, Bisexual or Transgender (LGBT) communities

8.10 LGBT communities are affected by dementia both as patients and carers.

8.11 The Equalities Action Plan for the National Dementia Strategy (Department of Health) estimates that 5-7% of the population is LGBT indicating that 34,000 LBGT people are living with dementia.
The Alzheimer's Society also estimated between 35,000 and 70,000 LGBT people care for someone with dementia in the UK.

8.12 Another estimate from the Integrated Household Survey in 2011/12 found that 1.5% of adults in the UK identified themselves as LBGT. However, the prevalence differed with age. For example 2.7% of 16 to 24 year olds were LGBT compared with 0.4 % of 65 years and older.

8.13 There is no specific data on dementia amongst the LGBT community in Devon. However, crude estimates from the recent LGBT Health Needs Assessment estimated that there were 14,281 LBG people in Devon in 2013.

Deprivation

8.14 There was little evidence that the prevalence of dementia varies by socio-economic status or deprivation and analysis from the dementia prevalence calculator also found no apparent correlation between deprivation and dementia prevalence.

8.15 Regarding incidence, a UK study in 2010 from 252 general practices showed that the incidence of dementia was higher in more deprived areas. In 60 to 69 year olds, dementia was 68% higher in the most deprived group compared with the most affluent group. In the 70-79 year olds it was 45% higher, in 80 to 89 year olds it was 11% higher compared with the most affluent group and no difference in the 90 year olds (and older).[30] The narrowing gap with increasing age groups is perhaps due to the most deprived groups also having a higher mortality rate generally compared with more affluent groups.

Dementia carers[31]

8.16 There are several estimates regarding the proportion of dementia carers. The Alzheimer's Society estimates that 11.2% of all carers looked after someone with dementia,[32] social services estimated 25%[33] and Devon Carer's Health Needs Assessment in 2008 estimated that 16.4% of carers looked after a person with dementia.[34]

[30] Rait Greta et al. Survival of people with clinical diagnosis of dementia in primary care: cohort study. British Medical Journal 2010 341:c3584.

[31] Dementia Carers Pathways, Devon, http://www.devonpartnership.nhs.uk/fileadmin/user_upload/publications/Strategies__plans_and_reports/Dementia_Carers_Pathways.pdf (accessed 14.2.14).

[32] http://www.alzheimers.org.uk/site/scripts/documents_info.php?documentID=546 (accessed 13.2.14) .

[33] Health and Social Care Information Centre (2010) Personal Social Services Survey of Adult Carers in England - 2009-10.

[34] A Health Needs Assessment for Carers: Young People and Adults in Devon, December 2008 http://www.devonhealthandwellbeing.org.uk/wp-content/uploads/2011/07/Carers-Health-Needs-Assessment-2008.pdf (accessed 4.1.2013).

8.17 A Health Foundation report [35] estimated that informal care work was 13 hours per week for mild dementia and increased to 46 hours for severe dementia. This emphasises the importance of supporting carers to maintain a good quality of life so that they can continue their caring role.

8.18 Older carers In Devon (65 years and older) are a higher proportion; 31% compared with 25% nationally and are projected to increase in the future.[36]

8.19 Evidence also suggests that older carers are often frail, in poor health and experience, stress, disturbed sleep and depression.[37]

9.0 Projecting Future Need In Devon

9.1 The nature of dementia means that it is important to differentiate the groups since some people who need services do not access them until a crisis point is reached. There are also people who demand services but could be better supported by different levels of provision. Social support was perceived to be greatest in the early stages and at the later stages.

Table 8: Numbers of late onset dementia in Devon with projections to 2030 (based on POPPI 2012 projections)

Age (years)	2012	2015	2020	2025	2030
65-69	678	721	636	676	766
70-74	1,076	1235	1518	1345	1439
75-79	1,901	2021	2404	2968	2664
80-84	3,043	3,128	3,508	4,226	5,256
85-89	3,411	3,555	3,861	4,517	5,534
90+	2,989	3,315	3,993	4,903	6,198
Total	**13,097**	**13,975**	**15,920**	**18,636**	**21,858**

9.2 Table 8 shows the POPPI estimates for late onset dementia in Devon for 2012. The number people with late onset dementia aged 65 years and older currently was 13,097 and is expected to rise by 22% in 2020 and by 67% (to 21,858) in 2030.

9.3 The older age groups had higher levels of dementia increasing exponentially with increasing age. For example, growth in the 60 to 65 age year olds will be stable at approximately 800 a year compared with over 90 year olds will double from 3,000 over 6,000 by 2030.

9.4 Figure 5a and 5b below reflect table 8 graphically. Late onset dementia will continue to be more common in women than men and that the gender pattern

[35] http://www.health.org.uk/publications/dementia-care/download-chapters/

[36] Annual Public Health Report 2010 -11, NHS Devon, Devon County Council.

[37] Improving services and support for older people with mental health problems, the second report from the UK Inquiry into Mental Health and Well-being in Later Life, Age Concern, 2007.

will increase in a similar manner over the next 20 years. In women, there will be a 64% increase and in men a 54% increase.

9.5 For age, exponential increases will be seen in people aged 80 years and older.

Figure 5a: The number of people with late onset dementia by gender, in Devon from 2012 to 2030 (based on POPPI 2012 projections)

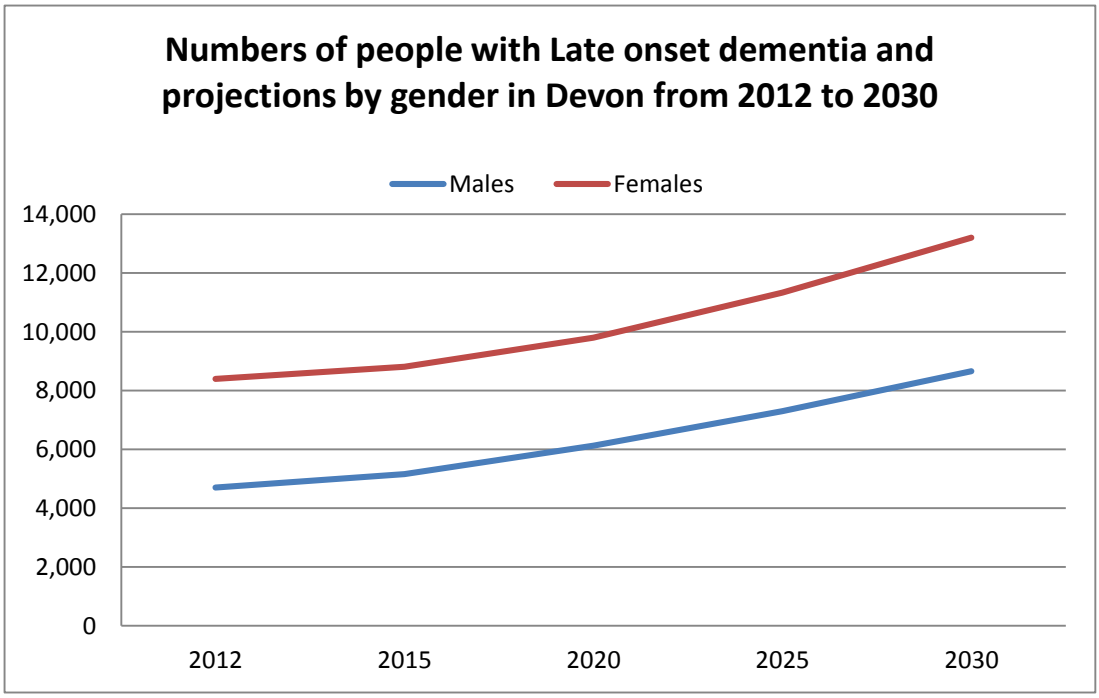
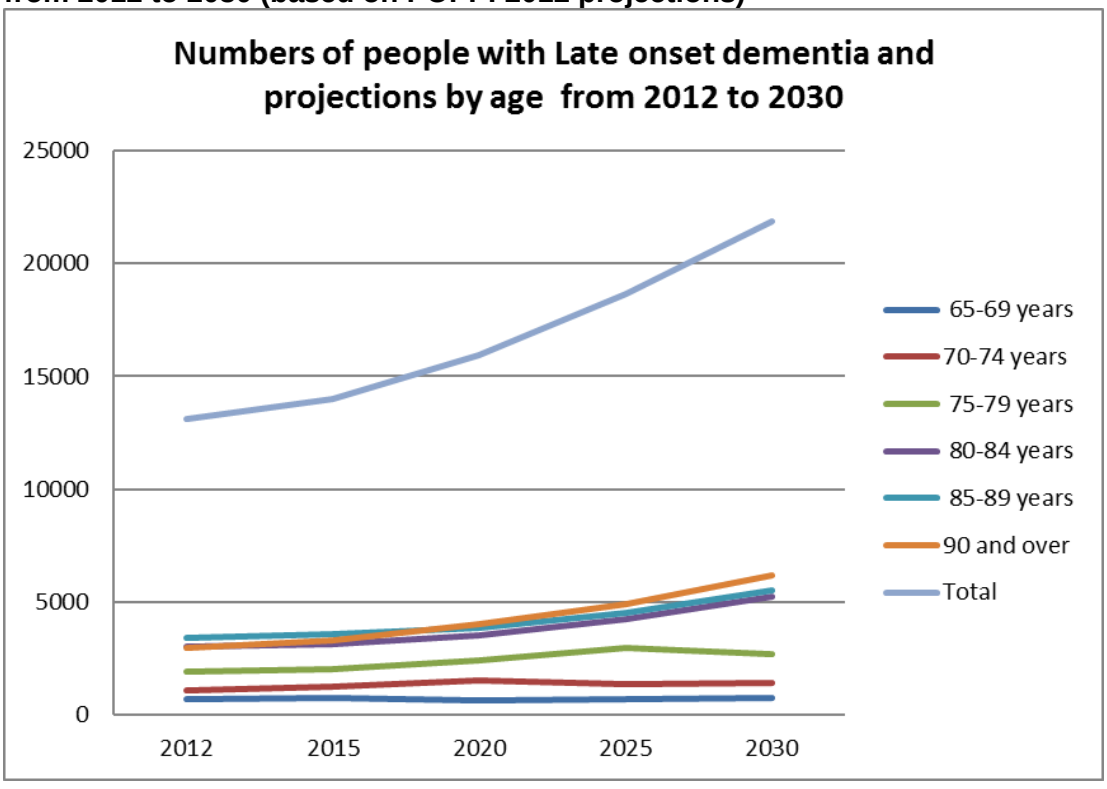


Figure 5b: The number people with late onset dementia by age in Devon from 2012 to 2030 (based on POPPI 2012 projections)



Cost of dementia

9.6 In 2007, the Dementia UK, 2007 report estimated that late onset dementia costs were £17 billion a year.[38] These costs included NHS care (7%), informal care (35%) and accommodation (40%) and social services (18%). The costs were based on 2005/06 data and were not available for early onset dementia.

Table 1: Estimated cost of dementia per person by severity 2005/06 (Dementia UK, 2012 report and NICE Dementia Costing Commissioning Assessment)

£	Cost of mild dementia in the community	Cost of moderate dementia in the community	Cost of severe dementia in the community	Cost of dementia in a residential care setting
NHS	2,508	2,430	2,639	1,334
Social Services	4,935	6,224	7,738	378
Informal Care	9,246	17,223	27,096	938
Accommodation	0	0	0	28,646
Total Cost	16,689	25,877	37,473	31,296

9.7 According to the Dementia UK, 2012 report dementia care costs £24 billion a year and are set to increase to £27 billion by 2018.

9.8 In Devon (based on 9.7 above) dementia cost were £333.6 million in 2012(£25,472 average per person x 13,097 people with late onset dementia) and this could increase to £556.8 million in 2030.

9.9 Since older age groups are at increased risk of dementia its worth considering future demand and planning formal care from mild, moderate to severe dementia and apportioning NHS and social care costs accordingly particularly as dementia care burden increases exponentially in the later part of dementia stage.

[38] National Institute for Health and Clinical Excellence. Dementia Costing Report – implementing NICE SCIE guidance in England, 2006. http://www.nice.org.uk/guidance/CG42 (accessed 20.2.13).

10.0 Prescribing Trends Nationally And Locally

10.1 Prescribing in the elderly population is complex and part of the National Dementia strategy is to reduce the levels of high prescribing of antipsychotic drugs nationally.

10.2 NICE guidelines recommends acetylcholinesterase inhibitors use (donepezil, galantamine or rivastigmine and memantine) for people with mild to moderate Alzheimer's disease where indicated.[39]

10.3 The National Dementia and Antipsychotic Prescribing Audit in 2012, was conducted in 3,850 GP practices and included 196,695 people with dementia showed that prescribing reduced from 17% in 2006 to 7% in 2011.

10.4 Reduced prescribing was also seen for newly diagnosed patients nationally; a reduction from 14% in 2006 to 4% in 2011.[40] The highest prescribing region; the North West reduced from 23% to 13%, Devon reduced from 16% to 6% and London (the lowest prescribing region) reduced from 8% to 2%.

10.5 Variation in prescribing patterns and the choice of anti-psychotics used was also found in acute care. The Royal College of Psychiatry 2009 audit showed that 16% of dementia patients (7,932) admitted to hospital were already on existing anti-psychotic drugs, a further 7% of patients were prescribed new drugs and further 5% were on existing and newly prescribed anti-psychotic drugs.

10.6 In nursing homes, it is estimated that 30% of patients are on antipsychotics compared with 10% of living in the community.[41] The high antipsychotic drug prescribing in care homes was highlighted in Devon's Joint Commissioning Strategy for People with dementia in Devon 2009-2013.

10.7 In 2011, it was estimated locally in Devon that 26% of dementia patients were on antipsychotics and of these only 20% were gaining benefit. This audit also found that 70% of those prescribed antipsychotic drugs had mild to moderate symptoms.[31]

10.8 Current research is inconclusive regarding whether statins stop cognitive decline or protect against vascular dementia and Alzheimer's Disease[42] and current NICE guidelines advise against prescribing statins as primary prevention for dementia.

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[39] National Institute for Health and Clinical Excellence (NICE). Dementia: Supporting people with dementia and their carers in health and social care. Clinical guideline 42. London: NICE; 2006.

[40] National Dementia Antipsychotic prescribing Audit, 2011. Health and Social care Information Catalogue. https://catalogue.ic.nhs.uk/publications/clinical/dementia/nati-deme-anti-pres-audi-summ-rep/nati-deme-anti-pres-audi-summ-rep.pdf (accessed 20.2.13).

[41] Shah, S.M. et al Antipsychotic Prescribing to Older People Living in Care Homes and the Community in England and Wales. International Journal of Geriatric Psychiatry, 2011. 26, 423–434.

[42] Menezes AR, Lavie CJ et al. The effects of statins on the prevention of stroke and dementia Journal of Cardiopulmonary Rehabilitation and Prevention 2012:32(5) 2; 240-249.

11.0 Dementia In Primary Care

11.1 In Devon, people with more established symptoms of dementia may be diagnosed in primary care. Ongoing clinical responsibility and management of people with dementia rests in primary care with advice, liaison and support from secondary care when necessary. People with mild, early onset, complex or unusual presentations are referred for memory assessment in secondary care.

11.2 The Quality and Outcomes Framework (QOF) assesses General Practices (GP) performance under the General Medical Services contract and in 2006, dementia indicators were introduced requiring GPs to have dementia registers.
It also required GPs to record the proportion of people with dementia reviewed in the previous 15 months. Of the people registered with a GP in Devon, 89% had completed their 15 month review according to Devon's audit in 2010/11.[43]

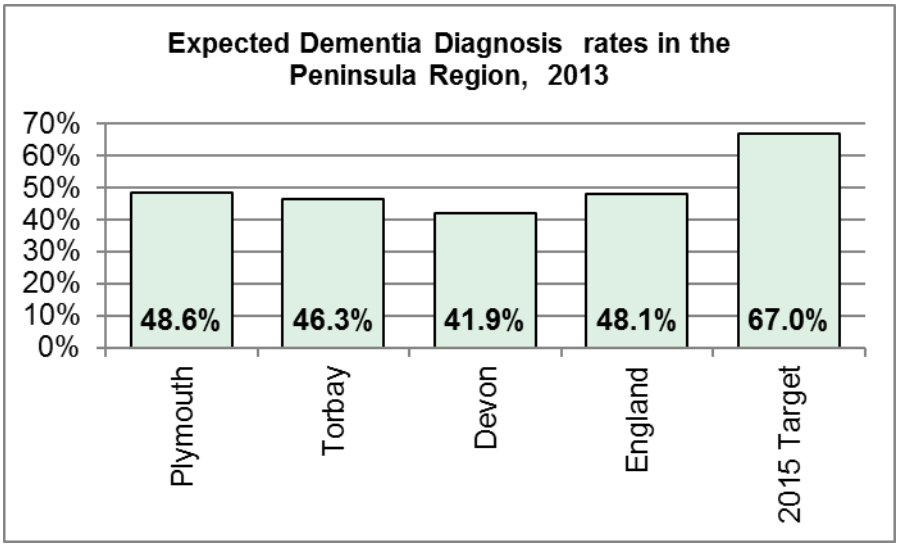
11.3 Dementia diagnosis is a high priority of the National Dementia Strategy. However, dementia screening in primary care at a population is not recommended by the UK National Screening Committee and the latest evidence does not supersede this recommendation (Dementia Evidence Review, page 5).
Dementia diagnosis rates are now monitored under the NHS Outcome Framework (Indicator 2.6i) and Public Health Outcomes Framework (Indicator 4.11).

11.4 The Alzheimer's Society recommends that diagnosis rates should reach 67% by 2015 and 75% by 2017. The South West Strategic Clinical Network's Dementia Implementation Group and Clinical Commissioning Groups felt that Devon would not be able to achieve the 2015 target.

11.5 The Devon Health and Wellbeing Outcomes Report showed in 2013, that 41.9% of people with dementia in Devon were on a GP register compared with 48.1% in England (Figure 6a below)

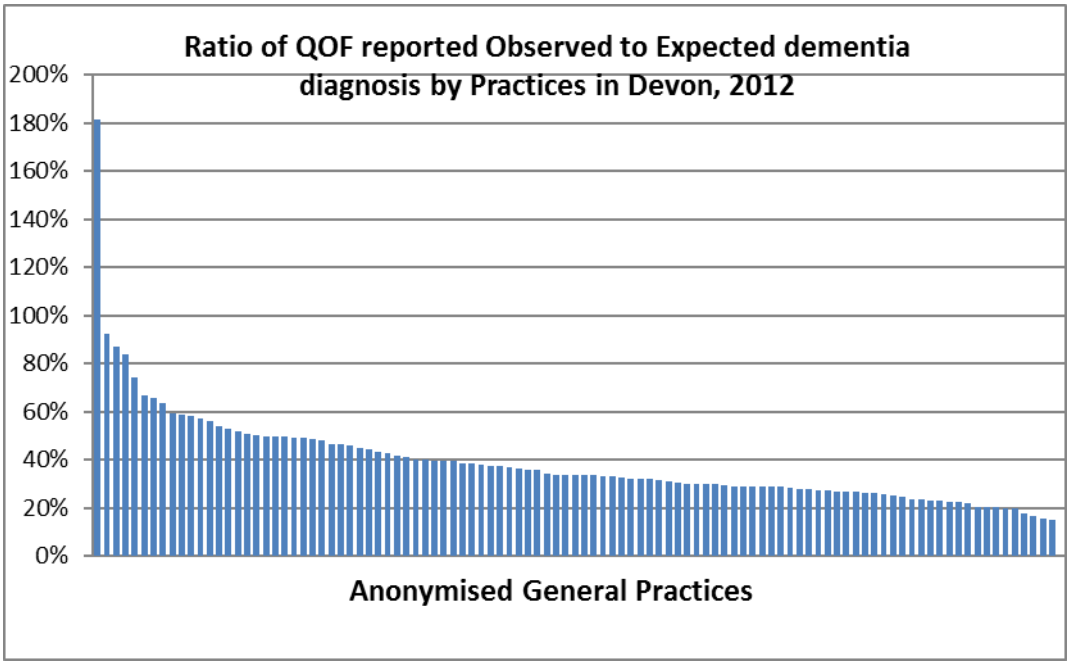
[43] Annual public health report 2010/2011 Older people, Devon County Council / NHS Devon

Figure 6a: Expected dementia diagnosis rates in the Peninsula region, 2013



11.6 The diagnosis rates are measured using the NHS Dementia Prevalence Calculator and applying age and gender prevalence rates from the Dementia UK, 2007 Report derived from studies between 1986 and 1993.

Figure 6b: Ratio of observed to expected recording of dementia by General Practices in Devon in 2012 (QOF and combined data)[44]

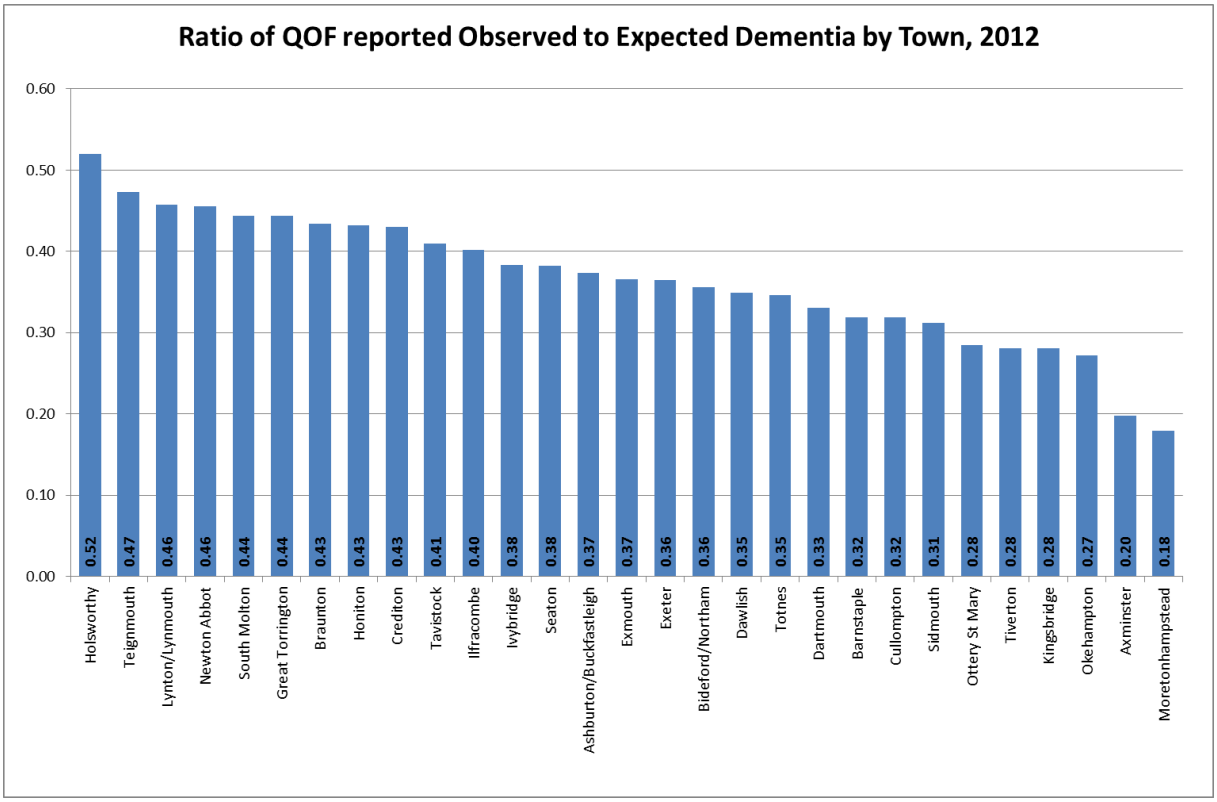


11.7 Figure 6b shows, the ratio of people with dementia recorded on a GP disease register as a percentage in 2011/12 from 104 General practices in Devon. On the upper end one practice had 80% of people with dementia were recorded and on the lower end, one practice had 16% of people recorded.

[44] Source: Quality and Outcomes Framework, Health and Social Care Information Centre, 2012; Alzheimer's Society Dementia in the UK Report 2007; and Exeter System Resident and GP Registered Population Dataset, 2012.

11.8 There was also an outlier practice with a dementia diagnosis of 180% (i.e 80% higher than expected). This was due to the high number of people registered with the practice from nursing homes, in light of a young population living in the area.

Figure 6c: Ratio of observed to expected recording of dementia by Devon towns in 2012 (QOF and combined data)



11.9 Figure 6c shows ratio of dementia recordings on GP registers by Devon towns. Holsworthy had the highest recordings, 52% of people with dementia recorded and Moretonhampstead the least, with 18% of people recorded.

Summary of evidence regarding primary care physicians and dementia
(Dementia Evidence Review, page 4-5)

11.10 There was evidence from lower quality studies mainly from the United States of wide variation in physician adherence to dementia guidelines. Obstacles to optimal dementia care included the disease severity, gaps in staffs' knowledge, skills, attitudes and resources as well as the added difficulty of differentiating between people with mild cognitive impairment and mild dementia. Lack of appropriate screening tools also added to the challenges.

Health Check Programme

11.12 From 1st April 2013 raising awareness of dementia has been included in the health check programme for individuals between 65 and 74 years old. The health improvement programme seeks to prevent cardiovascular disease; a risk factor for dementia.

12.0 Dementia In Secondary Care

Memory Clinics

12.1 Memory services are recommended by NICE guidance as a single point of referral for early diagnosis of dementia.

12.2 In Devon, people with signs of early onset dementia, mild / moderate dementia and complex presentations are referred by the GP for Memory assessment. Memory clinics are One Stop services where people undergo investigations and potentially a diagnosis of dementia.

12.3 A large proportion of attenders are diagnosed as having mild cognitive impairment rather than dementia and healthy lifestyle management is one option being explored to support this group.

12.4 Patients that are unable to attend a Memory Clinic in Devon due to frailty are diagnosed by Community Mental Health Teams.

Summary of evidence regarding memory clinics and dementia
(Dementia Evidence Review, page 7 and 11)

12.5 A study assessing cost effectiveness of early diagnosis and intervention calculated that investment in commissioning memory services would result in a 10% diversion of people with dementia away from residential care to be cost effective.[45]

12.6 For newly diagnosed patients, Memory clinic follow up was not more effective or more cost effective than GP follow up at one year.

12.7 Qualitative feedback from people with dementia and carers attending memory clinics highlighted that they valued regular communication and information. They also wanted support for those people without a dementia diagnosis or those that were unlikely to benefit from medication.

Hospital admissions for people with dementia

12.8 The National Audit for Dementia conducted by the Royal College of Psychiatrist estimated that 25% of all acute hospital beds are occupied by someone with dementia[46] but it could be as high as 40%.[47]

12.9 Dementia is difficult to manage and is complicated by comorbidities. Approximately 64% of people with dementia have 3 or more conditions.[48] In

[45] Banerjee S, Wittenberg R. Clinical and cost effectiveness of services for early diagnosis and intervention in dementia International Journal of Geriatric Psychiatry (2009) doi:10.1002/gps.2191.

[46] Findings of the National Audit Of Dementia Care in General Hospitals http://www.rcpsych.ac.uk/pdf/NATIONAL%20REPORT%20-%20Full%20Report%201201122.pdf (accessed 20.2.13).

[47] Singh et al 2013. The Rapid Assessment Interface and Discharge service and its implications for patients with dementia. Clin Interv Aging. 2013;8:1101-8

[48] Barnett K, Mercer SW et al. Epidemiology of multimorbidity and implications for health care, research, and medical education: a cross-sectional study. Lancet 2012

addition, very few validated instruments are available for dementia screening in general hospitals.[49]

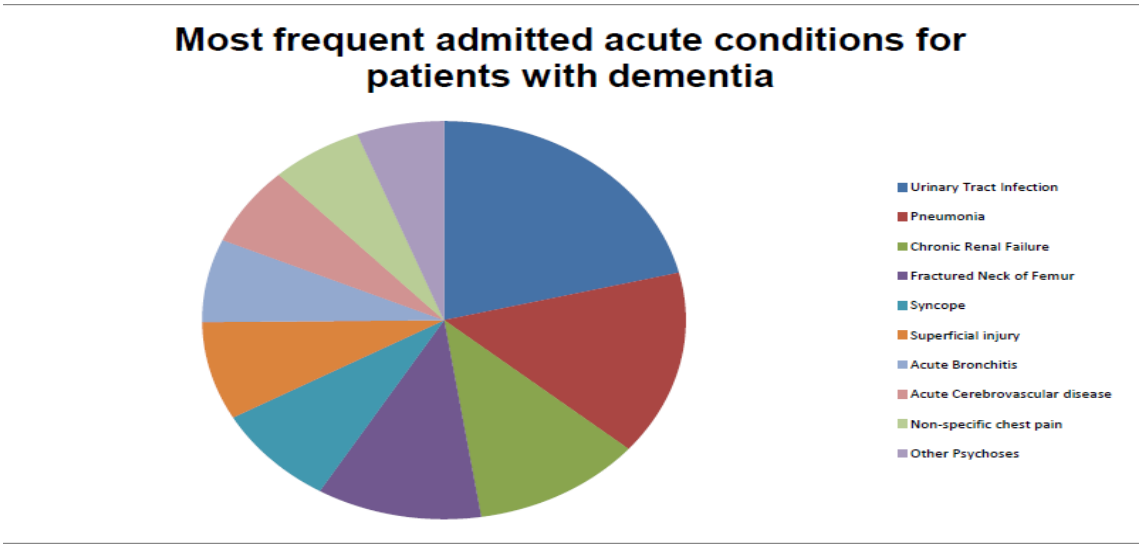
12.10 Regarding rural hospitals, evidence from lower quality studies mainly from Australia found that rural areas had fewer memory clinics, beds, elderly care staff and compared with urban hospitals. (Dementia Evidence Review, page 10-11). These findings may not be applicable in Devon, given that local services are provided by four acute hospitals and a number of community hospitals with lower bed numbers.

12.11 It is estimated that 20% of beds at the Royal Devon and Exeter hospital are occupied by people with dementia.[50] This may also be under reported if patients were admitted with other conditions and had dementia as a secondary diagnosis.

12.12 The South West Dementia Partnership, acute Trusts (including North Devon District Hospital; Royal Devon and Exeter hospital and the community hospitals), agreed action plans against NICE quality standards to improve dementia care and diagnosis in hospitals.[51] The results of their report are presented in section 12.13 to 12.19 below.

12.13 The report on dementia in the South West hospitals conducted by Dementia Action Alliance and National Institute of Innovation and Improvement in 2011 found that the most common acute admissions for people with dementia include urinary tract infections, pneumonia and fractured neck of femur (figure 7a).

Figure 7a: Top 10 acute admissions for people with dementia in the South West Region, 2011



[49] Jackson T A, Naqvi S H, Sheehan B. Screening for dementia in general hospital inpatients: a systematic review and meta-analysis of available instruments Age Ageing. 2013 Nov;42(6):689-95.

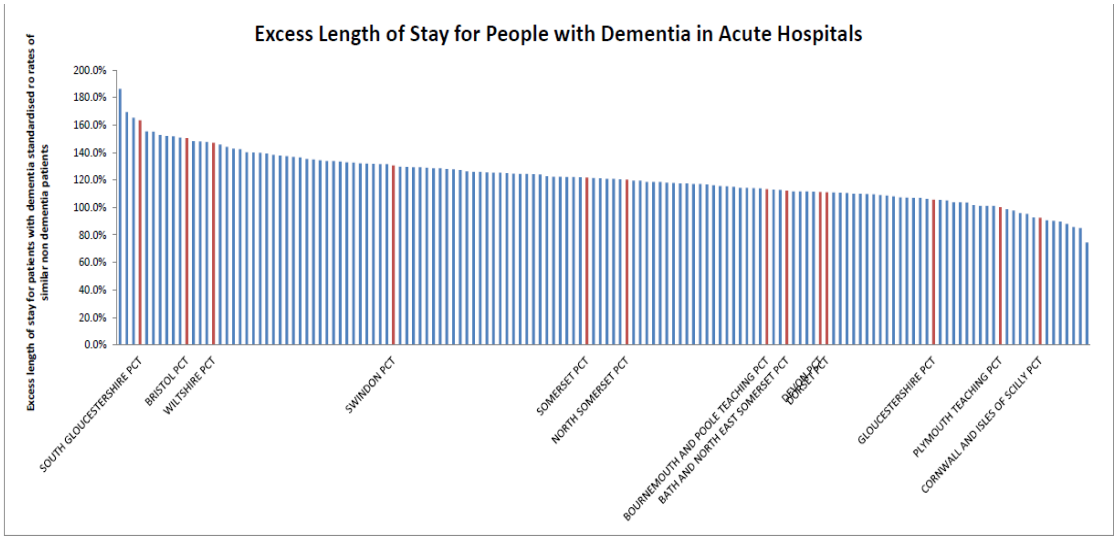
[50] Newsletter from NHS Devon, Plymouth and Torbay Cluster, February 2013 http://www.devonpct.nhs.uk/InfoPointLibrary/Communications_The_Month/february%20the%20month%20final.pdf (accessed 12.3.13).

[51] The Right Care, Developing Dementia Friendly Hospitals. Dementia Care in Acute Hospitals A Report from the Dementia Action Alliance South West Region, 2012. Devon Action Alliance, NHS Institute of Innovation and Improvement.

12.14 The average length of stay for people with dementia in this report was 13 days compared with 11 days for other patients. Discharges were 97.6% if dementia patients were elective admissions compared with 73.6% if they non-elective admissions.

A similar pattern was seen in the National Audit for Dementia discussed above. In addition, a higher proportion of non-elective admissions were placed in nursing homes after admission.

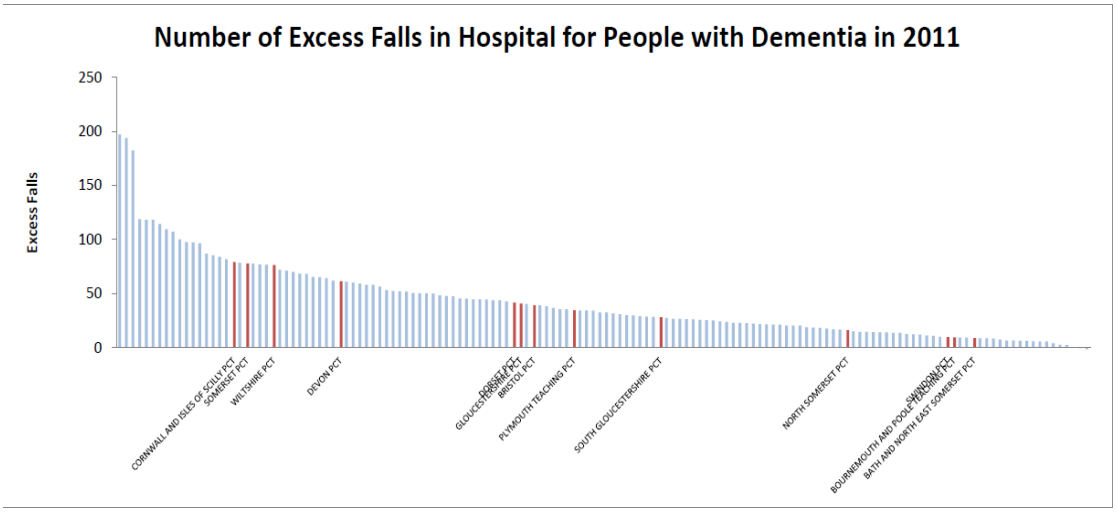
Figure 7b: Excess length of stay for people with dementia in hospitals in the South West region, 2011 (13 Primary Care Trusts in South West, pre April 2013)



Readmission rates for people with dementia

12.15 Dementia patients had higher readmission rates (8.2%) than other patients (3.5%) and even higher if they were non-elective admissions, 25% for people with dementia compared with 17% for other patients.

Figure 7c; Number of excess falls in hospital for people with dementia in the South West, 2011 (13 Primary Care Trusts in South West, pre April 2013)



Falls in hospital for people with dementia

12.16 Figure 7c above shows the number of hospital falls in patients with dementia and the expected number if they occurred at a similar rate with other patients. The proportion of falls was also higher if patients were admitted non-electively (2.4%) compared with electively (0.2%).

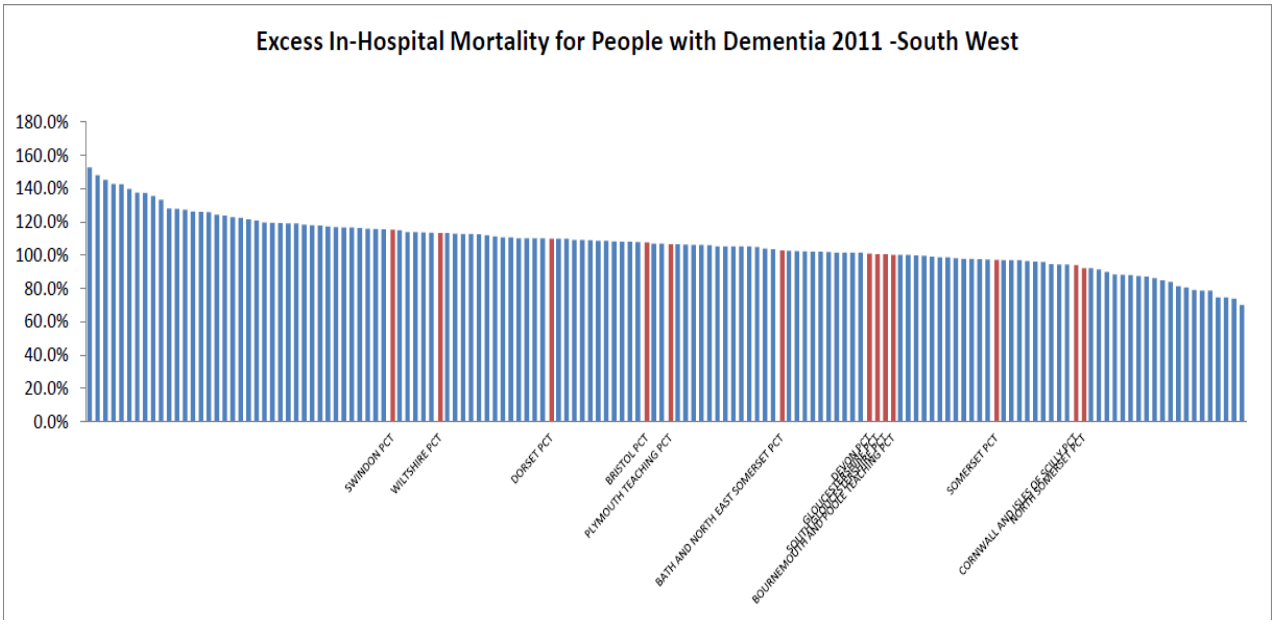
12.17 A systematic review in 2011 also showed that falls were three to 8 times higher for people with Alzheimer's Disease and that fall predictors included a history of falls, hypertension, impaired vision or depression.[52]

Excess hospital mortality for people with dementia

12.18 Figure 7d below shows the excess hospital mortality for people with dementia in 2011 from 13 Primary Care Trusts in South West as a ratio.

12.19 The highest mortality ratio was in Swindon at 118 (18% higher deaths than expected) and lowest was in North Somerset at 90 (10% lower deaths than expected). Devon's ratio was 100 (no excess deaths than expected).

Figure 7d; Excess in-hospital mortality for people with dementia 2011 (13 Primary Care Trusts in South West, pre April 2013)



[52] Jenson LE, Padilla R. Effectiveness of Interventions to prevent falls in people with Alzheimer's Disease and related dementias American Journal of Occupational Therapy (2011) 65(5).

Mortality estimates and dementia

12.20 In 2010, evidence from a large study on 22,529 people with dementia suggested that the likelihood of death was three times higher in the first year after a dementia diagnosis, compared with people with other diagnoses. Regarding age for people with dementia, 60 to 69 years olds' average life expectancy was 6.7 years compared with 1.9 years in those over 90 years old.[53]

12.21 According to the Dementia UK, 2007 Report approximately 10% of deaths in men and 15% of deaths in women are related to late onset dementia (60,000 deaths a year). It also suggested that delaying the onset of dementia by 5 years would halve the number of deaths.

13.0 Dementia And End of Life Care

13.1 In Devon, the Strategic Clinical Network are leading on improving the end of life care for people with dementia as part of the NICE Commissioning Guidance and the national Dementia Strategy for people with dementia.

13.2 This includes advice on supporting people and their carers to have early discussions about Capacity, Power of Attorney and Advance Directives.

13.3 NICE highlights that planning can be difficult for people with dementia as memory and communication skills decline making it difficult for them to articulate their preferences and wishes for end of life care.

Summary of evidence regarding end of life care and dementia (Dementia Evidence Review, page 23)

13.4 There was moderate evidence mainly from studies from the United States that end of life care services relating to patients with dementia is beneficial. With further research being recommended to provide tailored services.

13.5 Only a minority of nursing home residents with advanced dementia received hospice care, however it reduced unmet needs in the last days of life.

13.6 In the nursing home setting, the quality of end of life care was better if provided from specialist teams. There was limited evidence for advanced care planning in nursing homes and most studies recommending further research and more accurate tools to help referral criteria of dementia in end of life care.

[53] Rait Greta et al. Survival of people with clinical diagnosis of dementia in primary care: cohort study. BMJ. 2010 Aug 5;341:c3584. doi: 10.1136/bmj.c3584341:c3584.

14.0 Dementia and Social Services Available In Devon

14.1 This section looks at the services accessible in Devon to support people with dementia and their carers it also provides a summary of related evidence that was found regarding a particular service.

Social care services in Devon

14.2 Social care assessment is governed by national guidelines from the Department of Health, called Fair Access to Care Services (FACS). If support appears to be needed, an assessment will be undertaken to decide if the person qualifies for a service.

14.3 Services are provided for people in critical or substantial bands and have no-one willing or able to help them. People who are not eligible for services can still get information about available support from other providers from the Community Directory. In Devon, referrals for social care support are made via Care Direct.

Intervention groups

14.4 Once a diagnosis is made, people with dementia are offered support through a five week programme of education sessions delivered jointly by North Devon Health Care Trust, Devon Partnership Trust and the Alzheimer's Society.
These Memory Matters groups support newly diagnosed people with dementia and their carers to understand the condition and provide coping strategies.

14.5 Additionally support is also provided for people with established dementia that are having significant difficulty coping with their symptoms and diagnosis. Living Well with Dementia groups offer further support through a therapy based approach over a six week programme.

Alzheimer's Society dementia support service

14.6 The Alzheimer's Society is contracted by the Devon County Council to provide one on one support workers to people with dementia and carers at diagnosis as part of the National Dementia Strategy. They offer advice and support on maintaining independence either face to face, via telephone or email. The Alzheimer's Society also provides other services including general information through leaflets or local signposting to singing for the brain sessions.[54]

Complex care teams

14.7 Complex care teams in Devon provide a joint health and social care response, locally co-ordinated to promote independence and support people with complex needs to remain in their own homes or as close to home as possible. The aim is to improve outcomes for adults with long term conditions or complex needs to prevent further decline, hospitalisation and long term care. Teams proactively case find adults and their carers and

[54]https://www.alzheimers.org.uk/site/custom_scripts/services.php?serviceCode=2156&branchCode=14540&areaBC=WESW (accessed 11.2.14).

support geographical communities or 'cluster' populations between 30,000 and 35,000 in partnership with primary care and public health.

14.8 Community Mental Health Teams work alongside complex care teams to support people with additional complex mental health or dementia presentations.

Direct payments

14.9 These are payments made by Devon County Council, the Social Service department enabling the people who have had a social care needs assessment to receive services or to pay directly for services provided by other care provider organisations such as the voluntary sector and community groups. Personal budgets also allow people to have greater choice and make decisions about how their care is delivered.

Devon County Council day services[55]

14.10 Day services including day care and day treatment in Devon are currently being reviewed. This is partly due to the 66% fall in attendance to Day Centres (since 2005) which may reflect that more people pursue other interests or are attending activities memory cafes or luncheon clubs instead.

Summary of evidence for day services and access
(Dementia Evidence Review, pages 19-20)

14.11 The evidence around providing day services requires an understanding of service utilisation. Carers' reasons for not attending services were from lower quality Australian studies estimating that 33% of day / respite services were not being used. Major reasons for non-attendance included carer's strong belief of not benefitting, access issues and low social support to attend services.

Community mentoring service

14.12 Community mentoring help maintain social engagement for people with dementia and can help them have a valued social identity, well-being and quality of life. The mentoring service in Devon is part of the day care services and is also undergoing review.

14.13 It offers advice, support and help if carers are experiencing difficulties because of isolation, stress, depression or anxiety.

Background on care homes (nursing and residential homes)

14.14 Nationally it is estimated that there are 215,000 people with dementia living in public and private care homes.

The Dementia UK, 2007 report estimated that 67% of people with late-onset dementia live in their own home (or community) and 39% live in a care home (nursing or residential home).

[55] http://www.devonnewscentre.info/council-launches-consultation-following-day-service-review/ (accessed 14.2.14).

Almost 80% of residents in EMI (Elderly Mentally Infirm) registered homes have dementia compared with 67% in nursing homes and 52% in residential homes. Approximately 20% of those with dementia were in a home that was not a specialist in dementia care.

Local care beds in Devon

14.15 In Devon, POPPI estimates that 8,314 people over 65 years are currently in care homes and this will increase to 9,730 by 2020.

14.16 Recent social services intelligence for Devon estimated that approximately 40% of nursing home residents and 37% of residential residents had dementia. However, estimates were based on care homes which offered dementia services.

Dementia Centres of Excellence[56]

14.17 Devon County Council in partnership with Stirling University are building two Dementia Centres of Excellence for people with Dementia at Mapleton in Newton Abbott and Woodland Vale in Torrington. They are due to be completed during 2014 and will provide homely units for twenty people as well as benefit other people with dementia and their carers in local communities.

Extra Care Housing

14.18 There are two Extra Care Housing schemes in Devon which are managed under the Care Homes and Housing strategy to ensure that people with dementia would be provided with Extra Housing Scheme. Extra care housing provides modern, purpose-built homes that enable people to maintain their independence, while providing continuous access to care.

Summary of evidence for care homes, Centres of Excellence and Extra care housing (Dementia Evidence Review, pages 17-19)

14.19 There were few high-quality studies which found some evidence that enhancing environments in nursing / care homes improved function and agitation but not psychosocial outcomes. The national evaluation from the King's fund showed that Enhanced Environments Homes reduced falls, violence and aggression and Extra Care Housing (Special care homes) seemed to reduce functional decline during the first six months and improve quality of life at 18 months.

In House domiciliary care:

14.20 Also known as home help or home care provides a number of services for a person in their own home, to keep them as independent as possible. The service is now part of a social care re-enablement service in Devon. People requiring care at home will be supported by independent domiciliary care providers.[57]

[56] http://www.devonnewscentre.info/anne-marie-morris-mp-for-newton-abbot-to-visit-centre-of-excellence-for-dementia/ (accessed 14.2.14).
[57] http://www.devon.gov.uk/index/socialcarehealth/dementia/dementia-awareness.htm (accessed 14.2.14).

Summary of evidence (Dementia Evidence Review pages 20-21)

14.21 The evidence regarding care work is patchy and overall, a stronger need exists to evaluate which interventions work in the community.

14.22 One study found that care manager support helped improve dementia detection but carer support didn't extend staying at home for people with dementia.

Dementia friendly communities

14.23 There are approximately 18 communities in Devon working towards becoming dementia friendly. Libraries are also working closely with the Alzheimer's Society to have information available about dementia.

14.24 Public awareness in Devon includes the national pilot programme in primary and secondary schools that is incorporating dementia education into mental health training and possibilities of volunteering at care homes.

Memory cafés

14.25 In 2013, there were 38 memory cafes across Devon run by local voluntary and community sector agencies in partnership with the NHS and Local Authorities. A memory café is an open access drop in centre, held regularly and provides information and peer support for anyone worried about memory loss or their family or carers.

14.26 They are often attended by a community psychiatric nurse or health professional from an Older Person Mental Health Team. A formal referral is not necessary but people are signposted to memory cafes by GPs, the memory service, social services, voluntary sector, and hospitals or by word of mouth.

Summary of evidence on information giving and peer support
(Dementia Evidence Review, page 14-15)

14.27 There was evidence that information giving improved quality of life for people with dementia and their carers. There was low evidence that internet support was beneficial for carers and telecare services required more robust evidence before recommending its use.

14.28 Peer support networks appeared to improve wellbeing and quality of life for people with dementia as well as providing a gap in services earlier in the pathway but its cost effectiveness was unclear.

Devon Carers Organisation

14.29 Devon Carers are a voluntary organisation providing unpaid informal care to family members, friends or neighbours having long-term physical or mental ill-health or disability.[58] Devon Carers are commissioned by Devon County Council and the NHS to provide services.

[58] Dementia Carers Pathways, Devon, http://www.devonpartnership.nhs.uk/fileadmin/user_upload/publications/Strategies__plans_and_reports/Dementia_Carers_Pathways.pdf (accessed 14.2.14)

Take a break

14.30 'Take a Break' scheme, provides short breaks for carers in people's own homes, allocated three hours per week which can be saved and used in blocks of up to 12 hours at any one time. Every three months a carer will receive 39 vouchers in the post; with each voucher being equivalent to a one hour break.

Flexible break grant

14.31 The scheme enables flexible breaks to be taken by the carer. For example the grant can be used for holidays, hobbies and leisure activities.

Respite care

14.32 Respite care is short-term care alternative that gives carers a break. They can take a holiday either at home or away. Respite care may also be needed if the carer goes into hospital or has other commitments.

14.33 There was no reliable evidence from the literature that respite care either benefits or adversely affects care for people with dementia or carers (Dementia Evidence Review, page 19-20).

Emergency response card scheme

14.34 The scheme provides a link to a 24 hour help number. It enables emergency care (agreed in advance) to be provided if the carer is ill or cannot continue with their caring responsibilities.

Older people mental health assessments

14.35 There were no national estimates for people with mental health that are in care homes.

14.36 The data from Devon Social care local estimates show that 77% of older people with mental health problems assessed by social care services were estimated to have dementia in 2011/2012. This compared with 48% in the South West and 52% in England.

This equates to 14.4% (1,890 / 13,097) of the estimated dementia population in Devon. Tables 10a below.

Table 10a: Completed assessments for people aged 65+ with mental health problems, 2011/12 (local Social Care data, Devon County Council)

Clients during 2011/12	Devon	England	South West
Mental Health 65+	2,464	139,890	20,770
Estimates of Dementia 65+	1,890	73,285	10,015
	77%	52%	48%

14.37 The recording of 'dementia' is done by social care so it is unclear how many of these actually had a medical diagnosis of dementia. In addition, some people with dementia with physical disabilities may be reported in the physical disabilities / frailty categories rather than mental health.

Table 10b: Older people's mental health services 2012 compared with 2007 (local Social Care data, Devon County Council)

Care Type	Service Type	2012	2007
Community	Day Care	361 (17%)	370 (21%)
	Direct Payments	153 (7%)	29 (2%)
	Equipment & Adaptation	25 (1%)	-
	Personal Care	483 (24%)	414 (23%)
	Meals	99 (5%)	149 (8%)
Res & Nursing	Other/ Prof Services	19 (0%)	62 (4%)
	Nursing	166 (8%)	160 (9%)
	Residential (and respite)	777 (38%)	617(33%)
Total		**2,083**	**1,801**

14.38 Table 10 b shows that for older people's mental health services in Devon, there was an increase in the number of people receiving support (from 1,801 in 2007 to 2,083 in 2012). There was also an increase in direct payments (reflecting personal budgets) and residential care.
The table also shows reductions in day care service previously discussed.

15.0 Views of Local Carer Representatives and Stakeholders

15.1 This section reflects on stakeholder views from carer representatives and also service providers and commissioners in Devon and reflect on gaps in services perceived by stakeholders.

15.2 There are several published papers regarding viewpoints from people with dementia, their carers, service providers and commissioners on dementia services. They provide insight into their experiences of diagnosis, the challenges faced with services and make suggestions for future improvements.

Attitudes, beliefs and feelings around becoming a person with dementia or carer.[59]

15.3 In 2012, a systematic review of 28 qualitative studies on 3,095 people with dementia (or mild cognitive impairment) and carers about adapting to a dementia diagnosis was conducted. Participants were mainly from the UK or United States.

15.4 Participants' experiences of barriers to early diagnosis included; stigma, long waiting lists, lacking awareness of dementia symptoms. Having a dementia diagnosis led to frustration, a desire to preserve normal identity and altered family relationships. However, for dementia carers having a diagnosis was a relief from uncertainty.

15.5 Patients and carers also welcomed strategies to reduce the impact of dementia. They stated that signposting for health and social services had improved, however more support post diagnosis was required and information needed to be flexible and provided regularly. For newly diagnosed patients, peer support and referrals to community support were also valued services.

15.6 Whilst comments were generally positive, they needed to be considered in the varied service contexts, dementia types and patient / carer experiences. As well as managing their expectations pre and post diagnosis.

Carer views on dementia care in Devon compared with Dementia 2012 survey

15.7 Meetings with patient / carer representatives and stakeholders were held in October and November 2012.

15.8 The initial meeting was held with Devon Dementia Partnership Group (including Senior Voice, UNITE Carers Mid Devon, Carers Pathways / Memory Cafes, Alzheimer's Society, Devon Association of Community and Voluntary Services, Rotarians easing problems of Dementia (REPoD) representatives). These representatives forwarded the survey to Devon patients, carers and their representatives.

[59] Bunn F, Goodman C et al. Psychosocial factors that shape patient and carer experiences of dementia diagnosis and treatment: a systematic review of qualitative studies. PLoS Med. 2012 Oct;9(10):e1001331.

15.9 The survey was based on the Dementia 2012 report that conducted a national survey on how well people are living with dementia in England, Wales and Northern Ireland. The national survey had 309 responses from people with dementia or carers. The national survey also looked at seven outcomes which people with dementia and carers said were useful to them.

15.10 A limitation of the local survey in Devon was that only a small number of carers responded and cognitive problems prevented patients completing the survey. Despite this, the local survey helped to provide a local perspective on service use.

15.11 Thirty three people completed the local survey in Devon. Most of the responders were carers attending memory cafes. The results are presented in Table 12 below.
Approximately a third were 70 years old or younger, a third were 71 to 80 years old and a third were 81 years and older.

Table 12: Survey responses from Devon dementia patient / carer representatives compared with Dementia 2012 national report

	Devon carers (n=33)	Dementia 2012 National report (n=309) on people with dementia and carers
What was the length of time taken to receive a diagnosis of dementia?		
Up to 12 months	45%	22%
1 to 2 years	19%	37%
3 to 4 years	16%	23%
5 to 6 years	6%	5%
Over 6 years	6%	3%
Don't know	6%	5%
If you have a carer (family or friend) are they supported to care for you (e.g. financially, social care support, informal support)?		
Always	33%	40%
Sometimes	22%	30%
No	39%	17%
Don't know	0%	3%
Don't have a carer	6%	8%
Not stated	-	3%
How well do people with dementia think their community understands how to help them live with dementia?		
Yes, very well	12%	12%
Yes, a little	15%	36%
Not very much	50%	25%
Don't know	23%	22%

How much would people with dementia like their community to understand how to help them to live well with dementia?

Yes, a lot	63%	57%
Yes, a little	11%	14%
Not very much	11%	8%
Don't know	15%	12%

How much better do people with dementia think their life would be if their community understood how to help them live well with dementia?

Yes, a lot	77%	45%
Yes, a little	8%	22%
Not very much	4%	7%
Don't know	12%	19%

How prepared is the general public in UK society to dealing with people with dementia?

Is very prepared	10%	2%
Fairly prepared	24%	15%
Neither prepared or unprepared	21%	15%
Fairly unprepared	34%	34%
Very unprepared	7%	26%
Don't know	3%	8%

What could be done in your community to help you live the life you want?

Better understanding of dementia / less social stigma	11%	25%
Publicity / more public awareness of the condition	10%	17%
Local activities / opportunity to socialise	8%	13%
More day trips out	4%	3%
More tolerance / patience from others	6%	7%
Community spirit / watch out for each other / more caring / helpful	7%	7%
Provide more information	6%	5%
Training for professionals / support workers	7%	5%
Improve bus services / cheaper forms of transport	2%	4%
Increased / better funding	7%	4%

Communication	6%	4%
Respite care	8%	3%
Education of young people	5%	2%
To be treated as an individual	6%	2%
More help/one to one help	6%	2%

15.12 The common viewpoints from Devon carers from this local survey included continuing support for social activities and outings. However, carers were concerned that they may reduce in future. Carers also felt that there were too many communication channels from various organisations which could be simplified, better coordinated and updated regularly. Their views were echoed in the literature. In addition, carers commented that Dementia patients had different needs because of the wide variation of dementia status.

15.13 The below are the additional views that carers provided for the survey.

Please could your comments on your experience of dementia and services.

'It all depends on the state of mind of the person with dementia. Some people are better educated and accept they have a problem. Others are not so ready to accept or admit they have a problem. My wife thinks she is fine and I am the one with problems. Hence she refuses help. This leaves us trapped in the house all day, life can then be a nightmare.'

Supporting carers was important and some felt they wanted more help. Comments below express some views.

'Practical and emotional support for carers is absolutely essential. I was a carer for my mother who died in 2004 and needed a care home from 1989. She had cancer and dementia. I appreciated all the help I received during those years especially respite facilities and support from the carer support worker'.

'I cared for my wife for 10 years but it got impossible for me. She has been in a care home for 7 years. I can't help sometimes but worry a lot now that she is 83. The care she received is quite good thank God.'

'My wife has problems with journeys by car in Devon's narrow roads. A local meeting would be appreciated to limit car rides. The memory clinic has been most helpful.'

Views from Devon commissioners and providers on dementia care

15.14 The Older People's Mental Health Working group and Devon Pan Devon Dementia Steering group were asked to complete a survey also in October and November 2012 to get their views on current services and suggestions for future improvements.

15.15 Stakeholders included primary and secondary care clinicians, commissioners, managers and service provider representatives from secondary care. They covered Devon County Council, NHS Devon, Devon Partnership Trust, Northern Devon Healthcare Trust, Royal Devon and Exeter NHS Foundation Trust.

15.16 Since most dementia crises are due to social breakdown, more social interventions are likely to help than psychiatric interventions. However locally, many GPs still perceive that a 24 hour older people mental health crisis service is important whilst evidence from other parts of the UK does not support the commissioning this service.

The questions and answers are provided below.

What are the current unmet needs across the system?

'The lack of crisis intervention, no CPN integral to the complex care team.'
'Poor prioritisation in referral of patients and standardised diagnostic pathway.'

'The need for; consistent memory assessment service, efficient post-diagnosis intervention service, good quality support for service users in community and to improve diagnosis rates so more people have access to services'

'There is currently a lack of OPMH support in terms of dementia crisis, specifically in prioritising these patients and allocating appropriate time from psychiatrists and community psychiatric nurses, we recognise this is due to the lack of capacity in the system.'

Where are there gaps in the treatment system?

'The capacity to provide on-going support and management'

'The lack of group treatment interventions for carers and newly diagnosed patients.'

'There's variable access to post-diagnosis interventions and community OPMH team responses across Devon. Some GPs refuse to prescribe Acetylcholinesterases under new shared care scheme. There's also variable provision of voluntary sector services e.g. singing for the brain.'

Who are the hidden populations and what are their risks?

'Those not approaching their GP with early onset memory problems are at risk of deterioration and presenting in a crisis.'

'Nursing home residents who are looked after by poorly trained staff in dementia and managing anti-psychotic drugs'

'Those diagnosed by a specialist but not on the GP register. They risk not receiving annual review of dementia and if admitted, hospital colleagues may not be aware that they have dementia.'

What are the enablers and barriers to treatment / management of the dementia pathway?

Enablers; *'The new pathway will certainly help to enable to management of dementia along with i.e, EDI memory clinics, DSWs.*

'Improving OPMH services, shared care drug prescribing, the new support worker service, the proposed new intervention services.'

Barriers: *'there's restricted resources to meet the growing needs of this population.'*

'The current system does not allow appropriate prioritisation of cases. There's a poorly defined pathway of care, not currently commissioned.'
'Therapeutic nihilism, lack of knowledge / confidence in dementia care.'

What improvements can be made to improve future service provision?

'Review the current service within OPMH and its re-configuration to ensure that a robust system is in place to provide on-going management and support for dementia patients and carers.'

'Defined care pathway is being worked upon with associated Key Performance Indicators'

'OPMH memory assessment service redesign. Robust pan-Devon intervention services. Dementia support worker service. GP education (already delivered to 70% of GPs). Improved care home education, standards and GP input.'

16.0 Discussion and Considerations

16.1 Dementia is a complex and incurable condition that is difficult to manage and has greater needs for health and social care as it progresses to the severe stage. It requires continued collaborative working to address the increasing prevalence of dementia over the next 20 years.

16.2 The number of dementia carers in Devon will also increase and would also need continued support services particularly as Devon carers are also older than the England average.
Alongside this, carers and patient representatives will benefit from continued support and better coordination between organisations regarding the information they provide.

16.3 In primary care, dementia diagnoses rates are increasing. These were 37.1% in 2011/12, 41.9% in 2012/13 and the most recent figure of 44.9% in 2013/14. Increasing diagnosis is a priority in the Joint Health and Wellbeing Strategy and Better Care Fund.

16.4 In secondary care, the South West Dementia Partnership and Acute Trusts agreed action plans against NICE quality standards to improve dementia care in Devon hospitals including diagnosis.

16.5 The previous milestones achieved by organisations and the Pan – Devon dementia group and the Older People Mental Health Steering group regarding dementia care in Devon were summarised in Figure 1. These included primary and secondary care staff training, having clinical leads in Devon for dementia, a dementia pathway to improve early diagnosis, established memory cafes, improved hospital care for people with dementia, a joint commissioning strategy with community and acute hospitals, GPs, commissioners and an implemented carers' strategy.

16.6 The latest Dementia Strategy 2013 to 2015, Figure 2 shows that Devon's priorities are GP education, timely diagnosis, peer support, dementia friendly communities, providing care closer to home and in care homes, providing information after diagnosis, improving end of life care, personalised support and carers support which had some evidence of benefit from the literature.

16.7 It is hoped that the Dementia Health Needs Assessment will help inform the current priorities on the Dementia Strategy in Devon on raising awareness and understanding, increasing Memory clinics, end of life care and support services for people with dementia and carers which evidence shows have elements of benefit.

16.8 Closer working relationships between health and social care as well as data access will also help map future dementia estimates of cost and growth with greater accuracy.

16.9 The groups with early onset dementia, BAME, LGBT communities and people with Down's syndrome although a small proportion in Devon would benefit from services tailored to their specific needs.

16.10 Overall, the findings from the Dementia Evidence Review did not supersede current NICE guidelines or national recommendations for dementia services. Most of the studies were mainly from Australia, Europe or the United States making them less applicable in the UK setting. Very few studies were found on economic studies or service models in rural settings similar to Devon.

16.11 The Dementia Evidence Review also highlighted the research gap regarding the currently commissioned services in the UK and the need for further research to strengthen the evidence base. The current increase in dementia research and funding will hopefully address some of these gaps.

16.12 This Health Needs Assessment overlaps and supports other related work such as long term conditions and integrated care as well as the Health Needs Assessments on care homes, mental health and carer's health in Devon.

17.0 Recommendations

17.1 The Dementia Health Needs Assessment recommends that commissioners, providers and stakeholders in Devon collectively build on the current work to improve the health and wellbeing of individuals with dementia and their carer's through the new Dementia Strategy. Some areas to highlight include:

- Awareness raising should focus on prevention as well as early diagnosis
- Increasing dementia diagnosis should remain a priority so that individuals are provided with the support they need
- The future projections for dementia diagnosis need to be considered in service design as the increase in diagnosis will be significant
- The needs of certain groups in relation to dementia need to be considered including BAME, LGBT communities, individuals with Down's syndrome and individuals with early onset dementia.

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September 2014

Appendix 1

Summary of national policies and strategies for dementia

Box 1: Objectives from National Dementia Strategy (2009)

1. Improving public and professional awareness and understanding of dementia.
2. Good-quality early diagnosis and intervention for all.
3. Good-quality information for those with diagnosed dementia and their carers.
4. Enabling easy access to care, support and advice following diagnosis.
5. Development of structured peer support and learning networks.
6. Improved community personal support services.
7. Implementing the Carers' Strategy.
8. Improved quality of care for people with dementia in general hospitals.
9. Improved intermediate care for people with dementia.
10. Considering the potential for housing support, housing-related services and telecare to support people with dementia and their carers.
11. Living well with dementia in care homes.
12. Improved end of life care for people with dementia.
13. An informed and effective workforce for people with dementia.
14. A joint commissioning strategy for dementia.
15. Improved assessment and regulation of health and care services and of how systems are working for people with dementia and their carers.
16. A clear picture of research evidence and needs.
17. Effective national and regional support for implementation of the Strategy.

Box 2: Commitments from the Prime Minister in his personal challenge on dementia in 2012: Delivering major improvements in dementia care and research by 2015.

1. Increased diagnosis rates through regular checks for over-65s.
2. Financial rewards for hospitals offering quality dementia care.
3. An Innovation Challenge Prize of £1m.
4. A Dementia Care and Support Compact signed by leading care home and home care providers.
5. Promoting local information on dementia services.
6. 20 dementia-friendly communities across the country.
7. Support from leading businesses for the PM's Challenge on Dementia.
8. An awareness-raising campaign.
9. More than doubling overall funding for dementia research to over £66m by 2015.
10. Major investment in brain scanning.
11. £13m funding for social science research on dementia (NIHR/ESRC).
12. £36m funding over 5 years for a new NIHR dementia translational research collaboration to pull discoveries into real benefits for patients.
13. Participation in high-quality research.

Box 3: NICE draft social care quality standards for people with dementia:

1. People who are concerned that they or someone they know may have dementia are listened to and have opportunities to discuss such concerns.
2. People who might have dementia are informed of the benefits of attending a memory assessment service and encouraged to do so.
3. People living with dementia and their carers are in contact with a local adviser who provides information about dementia and how to access additional support.
4. People living with dementia and their carers have choice and control in decisions affecting their care and support.
5. People living with dementia have a care and support plan based on individual needs.
6. People living with dementia and their carers take part in a review of their care and support needs when their circumstances change and at least once a year.
7. People in the early stages of dementia and their carers have opportunities to be involved in planning their palliative and end-of-life care.
8. People living with dementia are supported to participate in activities based on individual interest and choice.
9. People living with dementia are supported to maintain relationships and have opportunities to contribute to the wider community.
10. People living with dementia are supported to access services that help maintain their physical and mental wellbeing.
11. People living with dementia have their accommodation designed or adapted to meet their specific needs.
12. People living with dementia and their carers have opportunities to be involved in planning and evaluating services.
13. People living with dementia and their carers are supported to access independent advocacy services.

Appendix 2

A Literature Review for dementia services in primary care, secondary care and social care

This evidence review was conducted as part of the rapid Dementia Health Needs Assessment conducted in 2013 to support commissioners in decision making for services that reflected local needs in primary, secondary and social care settings in Devon.

Search strategy

Health services interventions in primary, secondary, social care and end of life care relating to dementia.

Searches were limited to peer-reviewed articles, published in English. This yielded 5,784 results and included studies from 2003 to January 2014. The searched databases included MEDLINE, EMBASE, CINAHL, TRIP, NHS Evidence, Google Scholar, SCIE, the Cochrane Collaboration Library. The Kings Fund site, Alzheimer's dementia website, Department of health and a general internet searches were also conducted.

The search terms used for health services articles relating to dementia contained key words 'dementia' 'memory disorders', 'Alzheimer's disease', 'cognitive decline' 'carers' 'senile decay' 'effectiveness' 'value' 'prognosis' ' follow up' 'value' 'benefit' 'follow up' 'social care' 'domiciliary services' 'housing' 'assistive technology' 'care homes' 'residential home' 'education' 'support services' 'primary care' 'secondary care' 'services' 'day services' 'specialist services' 'housing' ' assistive technologies' 'care' 'education support services'.

Evidence reviewed

An evidence hierarchy was followed prioritising systematic reviews and randomised controlled trials to produce the highest quality of best evidence. Where these were lacking then lower hierarchy studies were reviewed (e.g. from qualitative studies, service evaluations, observational studies).

Studies on dementia services were summarised to give an overview of the evidence available. Studies concentrating on specific types of dementia or pharmacological interventions were not included in this review. NICE guidance and quality standards were also not included or discussed since they were discussed in a recent rapid review for dementia. Approximately 100 papers were reviewed.

A summary of the literature reviewed has been produced and is available on request.