Joint Strategic Needs Assessment 2013

Dementia Health Needs Assessment

Doncaster Data Observatory

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		of the Doncaster Dementia Alliance
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i Executive Summary

i.i Population

In Doncaster 51,500 people are aged 65 plus (17%) and 6,500 are aged 85 plus (2%). By 2030 these numbers may increase to 73,400 and 11,900 respectively.

Older people are not spread uniformly across the Borough; the proportion aged 65 plus ranges from 13% in Wheatley Ward to 25% in Torne Valley Ward.

The population of Doncaster is not ethnically diverse compared to regional and national averages, though there is a sizeable gypsy/traveller population.

Doncaster ranks in the 12% most deprived local authority areas, though deprivation varies greatly between Electoral Wards.

Around 19,500 people aged 65 plus are living alone (split approximately two thirds female to one third male). By 2020 this may rise to nearly 22,300.

The 2011 Census recorded 33,150 people providing unpaid care, of which 9,383 committed 50 hours or more per week. 7,301 people aged 65 plus provided unpaid care, 14% of people in this age group.

Carers experience poorer health; 7% of non-carers report bad or very bad health compared with 14% of people providing 50 or more hours a week.

i.ii Epidemiology of dementia

There are estimated to be 3,697 people with dementia in Doncaster; 83 with the young onset form (<65 years) and 3,614 with the late onset form (\ge 65 years). By 2015 this may increase to 4,034 as the population ages (a rise of 9%).

There are thought to be 990 new cases of dementia each year in Doncaster.

More males have young onset dementia than females (60% to 40%), an imbalance that is reversed in late onset dementia (65% females to 35% males).

Based on the age and gender of the Ward populations, the Wards with the highest estimated cases of dementia are Bessacarr & Cantley (266 cases), Torne Valley (209), Finningley (197) and Thorne (195).

The picture is slightly different when looking at prevalence (the density of cases in the older population). Wards with the highest prevalence are Bessacarr & Cantley (8.4% of people aged 65 plus), Town Moor (7.8%) and Wheatley (7.7%).

Alzheimer's disease is the most common type of dementia, estimated at 2,292 cases in Doncaster. It is estimated that 998 people have vascular dementia or a mixture of Alzheimer's disease and vascular dementia.

In terms of severity, 460 cases may be classed as severe, 1,203 classed as moderate and 2,034 classed as mild.

It is estimated that 2,593 people live with dementia in the community and 1,104 people live with dementia in residential care.

i.iii Service Utilisation

2,001 people are registered for dementia with their GP in Doncaster, or 54.1% of the estimated total. This places Doncaster in the best 10% in the country, though this still leaves a 'diagnosis gap' of 1,696 people.

There is variation between GP practices. The lowest diagnosis rate is 27% and the highest 100%, so there may be opportunities to share good practice. GPs are achieving well in the QOF indicators relevant to dementia.

Prescriptions for the main dementia drugs have increased in recent years, both in numbers of items and costs, mirroring national trends. Improved identification of patients explains some, but not all, of this increase.

Pharmacies could play a wider role in dementia through awareness campaigns, medicine reviews, screening for dementia and making referrals to memory clinics.

327 residents aged 65 plus receive social care for dementia. This equates to 9% of estimated prevalence and 16% of the cases known to NHS primary care. Four residents under the age of 65 receive social care for dementia. There may be a shortfall of people with dementia accessing social care.

An estimated 1,104 people are living with dementia in care homes, but only 218 clients with dementia receive residential or nursing care from Doncaster MBC. There may be people with undiagnosed dementia in care homes that do not meet their needs.

96 people with dementia personalised their care in 2012/13; 72 with personalised home care, 34 with personalised day care, eight with direct payments and two with professional support.

The telecare service received 173 referrals for dementia, Alzheimer's disease or memory prompts over one year. There were 100 installations over the same period, the vast majority for property exit sensors. There is scope to increase the uptake of telecare with associated safety and peace of mind.

152 people were admitted to hospital with a primary diagnosis of dementia in 2012/13, a slight reduction on past figures. 2,386 were admitted with a secondary diagnosis of dementia - an increase of 60% on five years ago.

Many admissions with a secondary diagnosis of dementia are avoidable with appropriate community interventions, such as infections and falls.

People with dementia spend longer in hospital and have higher rates of readmission than older people in general.

Older People's Mental Health Services recorded the following activity over a recent one year period; Memory Clinics - 695 patients monitored, vascular Consultants - 135 new patients, Care Home Liaison Team - 537 referrals, Hospital Liaison Service - 1,086 referrals, Young Onset Dementia Service - 127 referrals.

The Hospital Liaison Service is a pilot and underwent an evaluation. The service contributed to a reduction in falls and reduced length of stay for people with dementia. Ward staff believe the service improved the care of patients.

A new post for a Primary Care Liaison Nurse has been funded for 18 months from April 2013; promoting early diagnosis, reviewing processes and signposting to supports. This post will begin a rolling programme of engagement with GPs.

The Alzheimer's Society supported 1,373 people over a one year period, the majority being carers. There were 218 new referrals over the same period, half of which were self-directed. There is scope to increase social prescribing but this would need to be resourced.

There are 500 deaths per year in Doncaster with Alzheimer's disease, dementia or senility as an underlying or contributory cause - 17.5% of all deaths. A high number of these occur in hospital and a low number occur in care homes. The main priority in end of life care is to enhance the capacity and capability of District Nurses and nursing in care homes.

Dementia is predicted to cost over £43 million per year in Doncaster, spread across NHS, Social Services, informal caregiving and accommodation.

i.iv Service user and stakeholder voice

Service user and stakeholder voice has been gathered through three routes specific to Doncaster; research based on a sample of carers, stakeholder workshops on Dementia Friendly Communities and a consultation event to capture the local understanding of dementia.

Research shows that, in most cases, the carer initiates contact with a healthcare professional. This person's decision is dependent on the clarity of the condition, evidence that symptoms are worsening and the support of others to legitimise action.

On average it takes 3 years to reach a diagnosis from the onset of symptoms, with most of the delay occurring prior to engagement with healthcare professionals. Diagnosis rates may improve by targeting family members; increasing their knowledge of the symptoms, that these symptoms require a medical response, that it can be legitimate to contact a doctor on behalf of someone else.

The workshops on Dementia Friendly Communities found that dementia services are generally of good quality – that the main priority is to improve access to services and personalise care (diagnosis, referral and choice).

The dementia friendly agenda requires greater engagement from stakeholders outside health and social care (e.g. housing, transport). Some of the strategic goals require improved collaboration between departments and organisations, an example being support for people to remain in private accommodation.

The consultation event found that people delivering front line, day-to-day services feel they show patience with people showing the symptoms of dementia. However, they expressed a need for workplace training to act more confidently. Many had concerns about members of the public, colleagues or family members but did not know how to address this.

These front line staff identified a number of positive and negative examples where services engage with people with dementia.

ii Priorities

A number of priorities have been identified in this needs assessment and approved by Doncaster's Dementia Alliance. These have been merged together and aligned with the three themes in the national dementia strategy;

Raising awareness and understanding of dementia

- Raise awareness and challenge preconceptions held by the public and patients. Communicate that the symptoms warrant a medical response, that there are benefits to early diagnosis, that people can 'live well' with dementia.
- Raise awareness and provide training for staff across all partner organisations (not limited to Health & Social Care) to make services more dementia friendly.
- Optimise the awareness role of partner organisations (e.g. contracted campaigns through pharmacies, information placed within libraries).
- Communicate the elevated risk of vascular dementia associated with high blood pressure, high cholesterol, smoking and diabetes. There is no treatment for vascular dementia so prevention is critical.

Early diagnosis and support

- Increase diagnosis rates and diagnose people at an earlier stage;
 - Reducing the disparity in diagnosis rates between GP practices.
 - Utilising pharmacies to screen for dementia and refer to Memory Clinics.
 - o Identifying people with undiagnosed dementia in care homes.
- Support carers, especially those providing full time care and those carers experiencing poor health themselves.
- Develop better support for people receiving diagnoses at an earlier stage.
- Support people with the less common forms of dementia and related issues such as learning disabilities and alcohol.

Living well with dementia

- Continue implementing Dementia Friendly Communities in Doncaster.
- Increase social prescribing whereby GPs refer to non-clinical services providing social, emotional or practical assistance. This requires support for the voluntary and community sector to accommodate any increase in demand.
- Ensure people with dementia access social care where necessary there is a gap between social care clients and the known number of NHS patients.
- Identify people with dementia in care homes to ensure their setting meets their needs - there is a gap between the known and estimated numbers in residential care.
- Promote personalised care for people with dementia and their carers.
- Increase uptake of telecare for people with dementia living in the community. This is most effective when introduced at an early stage.
- Ensure the prescribing of dementia drugs meets NICE guidelines and continue the reduction in the use of antipsychotics.
- Enhance the capacity and capability of District Nurses and nursing in care homes with regard to end of life care. Increase the propensity of GPs to visit care homes to tend to people at the end of life.

1 Introduction

1.1 Objectives

The objective of this needs assessment is to provide Doncaster's Health & Wellbeing Board with strategic priorities for dementia by;

- i) Describing the population at risk of dementia, highlighting particular characteristics relevant to Doncaster,
- ii) Estimating the current incidence and prevalence of dementia,
- iii) Detailing current and future need and service utilisation,
- iv) Undertaking a consultation to capture the local knowledge of dementia across various stakeholders and service providers.
- v) Summarise other projects in Doncaster relating to dementia,

1.2 <u>Background</u>

- 1.2.1 The term dementia describes a set of signs and symptoms including memory loss, mood changes and problems with communicating and reasoning. It is not a normal part of ageing. The condition is incurable though medicines can be prescribed for certain types of dementia that prevent the symptoms getting worse for a period of time. Dementia impacts the person with the condition but it also has a profound effect on their carer and on other people in their lives.
- 1.2.2 On a national scale, 670,000 people in England are living with dementia, and an estimated 21 million people know a close friend or family member with dementia 42% of the population. One in three people aged over 65 will go on to develop dementia in their lifetime (DH, 2012a).
- 1.2.3 The population is ageing and incidence of dementia is growing; numbers are expected to increase over the next 20 years, especially those with mild and moderate levels of severity (LGA, 2012). These trends will place an increasing demand on health and social care systems.
- 1.2.4 This needs assessment focuses on people with both early and late onset dementia. The assessment considers those people resident in the local authority area rather than patients registered with the Clinical Commissioning Group. It does not cover other forms of mental health in older people, such as depression, though there is some overlap with issues such as social isolation.

1.3 The National Dementia Strategy

- 1.3.1 A National Dementia Strategy, Living Well with Dementia, was published in 2009 (DH, 2009a). This identified 17 objectives that should improve dementia services and provide greater consistency across the country. The strategy objectives are divided into three broad themes;
 - Raising awareness and understanding of dementia,
 - Early diagnosis and support,
 - Living well with dementia.
- 1.3.2 Reluctance in seeking and offering help arises from a stigma of dementia and a false belief that the symptoms are a normal part of ageing (DH, 2009a). National awareness campaigns aim to improve understanding by the public and professionals alike.
- 1.3.3 The strategy highlights the value of early intervention both in improved quality of life and the economic benefits by delaying institutional care. Early diagnosis must be accompanied by appropriate information and interventions, including peer support and learning networks for patients and carers (DH, 2009a).
- 1.3.4 Living well with dementia requires community care, including carer needs, to be personalised. It requires developments in housing support and telecare, improvements in general hospital and intermediate care, and end of life pathways that meet the standards of the *End of Life Care Strategy* (DH, 2009a).
- 1.3.5 The National Institute for Health & Clinical Excellence (NICE) and the Social Care Institute for Excellence (SCIE) have produced guidance and quality standards that support the national dementia strategy. See Appendix 1 for further details.

1.4 <u>The Prime Minister's Dementia Challenge</u>

- 1.4.1 The Dementia Challenge was launched by the Prime Minister in March 2012, building on the national strategy and aiming to deliver major improvements in dementia care and research by 2015 (DH, 2012a). Three key areas are;
 - Driving improvements in health and care,
 - Creating dementia friendly communities that understand how to help,
 - Better research.
- 1.4.2 By 2015 up to 20 towns and cities will signed up to become more dementia friendly taking steps to towards being more inclusive of people with dementia.
- 1.4.3 Doncaster is working to become more dementia friendly. Doncaster MBC and NHS Doncaster CCG have commissioned AESOP Consortium to lead this agenda, capitalising on their experience from delivering the York project 'Dementia Without Walls' (Crampton, Dean & Eley, 2012). Consultations are

- on-going around four 'cornerstones' People, Place, Networks and Resources. The Doncaster Dementia Alliance will use these to plan the next steps.
- 1.4.4 An additional initiative, Dementia Friends, is being led by The Alzheimer's Society, seeking to inform and empower one million dementia friends by 2015. The programme is funded by the Department of Health and aims to improve people's understanding of dementia and its effects, supporting people to go about their lives and feel included in their community (Dementia Friends, 2013).

1.5 The dementia strategy in Doncaster

- 1.5.1 Local progress against the national strategy is monitored by the Older People's Mental Health Steering Group (now Dementia Alliance), the most recent report being *The Doncaster picture three years on* (OPMHSG, 2012).
- 1.5.2 Arrangements in Doncaster were largely ahead of the schedule set out in the Implementation Plan accompanying the national strategy namely in memory services, peer support, improved care in acute hospitals, improved care in care homes and workforce competencies.
- 1.5.3 Following the Prime Minister's Challenge in March 2012, NHS Doncaster CCG Leadership Forum (together with service users and carers) revisited the national strategy and the Doncaster Action Plan. The priorities for 2013/14 include three key areas that mirror the national strategy and/or dementia challenge;
 - Early diagnosis,
 - Developing dementia friendly communities in Doncaster,
 - Supporting carers (more relevant in Doncaster than research).

1.6 <u>Doncaster Health & Wellbeing Strategy 2013-2016</u>

- 1.6.1 A Health & Wellbeing Strategy has been produced for Doncaster's Health & Wellbeing Board. Mental health and dementia is one of five areas of focus for 2013/14 alongside obesity, alcohol, personal responsibility and families (Doncaster Shadow H&WB, 2012).
- 1.6.2 'These areas of focus do not replace individual organisational plans but identify those areas where all partners can contribute and need to work together to bring about significant improvements in health and wellbeing and reduce health inequalities in Doncaster' (Doncaster Shadow H&WB, 2012, p.10).

1.7 <u>Doncaster MBC Older Peoples' Commissioning Strategy</u>

- 1.7.1 Over the next five years commissioners will focus on early intervention and transform social care so that processes can respond to changing demand.
- 1.7.2 People's opinions will help determine the services commissioned, alongside the plans and priorities of partners. This will promote control and choice for people, their carers and their families, increasing happiness and independence.

2 Methods

- 2.1 <u>Methods in this needs assessment</u>
- 2.1.1 This assessment identifies need using quantitative and qualitative information. Numerical data describes the epidemiology of dementia and compares Doncaster against other areas supporting tables and charts are located in the appendices. Corporate methods capture the voice of service users, commissioners, providers and other stakeholders.
- 2.1.2 The epidemiological and comparative data originates from various sources;
 - Primary care data through the Quality Outcomes Framework (QOF),
 - Secondary care mental health provision from RDaSH,
 - Secondary care in the acute hospitals from NHS Doncaster CCG,
 - Service provision by community and voluntary sector organisations,
 - Prescribing data from NHS Doncaster CCG,
 - Provision of social care and telecare from Doncaster MBC,
 - Estimated figures from the NHSCB Dementia Calculator,
 - Demographic data from the 2011 Census and population projections from Projecting Older People Population Information system (POPPI),
 - Socioeconomic indicators from the Indices of Multiple Deprivation.
- 2.1.3 Corporate information was drawn from a consultation to capture the local understanding of dementia in Doncaster, a series of workshops to implement dementia friendly communities in Doncaster, and two research papers arising from a local study of 20 carers for people with dementia.
- 2.2 Limitations of the needs assessment
- 2.2.1 Low awareness of dementia and stigma of the disease means that many people do not seek diagnosis. Analysing demand for services will not provide the complete picture so these have to be combined with estimated figures.
- 2.2.2 Estimates from the NHS Commissioning Board's *Dementia Prevalence*Calculator may be insensitive for small populations such as GP practices. Also, the calculator uses a Doncaster population of 310,500 derived from patient postcodes. This is higher than the 2011 census population of 302,500.
- 2.2.3 This needs assessment uses the most up to date data, at the time of writing, from different sources. As a result the date periods may not uniform between sections or subsections.
- 2.2.4 Some systems are still based on paper records. This limits the level of detail that can be extracted.
- 2.2.5 Not all partners provided information when requested.

3 Population

- 3.1 The overall population
- 3.1.1 The 2011 Census recorded Doncaster's population at 302,500 (ONS, 2012a), an increase on prior estimates derived from the 2001 Census which fluctuated around 290,000. This higher figure increases the estimated dementia cases.
- 3.1.2 The age structure of Doncaster's population differs from that of England & Wales. A smaller proportion are aged 20-44 years and a higher proportion are aged 45-60 years. The disproportionate numbers aged 45-60 are likely to increase demand for dementia services in the future. See Table 1 and Appendix 1.

Table 1 – Doncaster population by broad age group

Age Range	Population	% of the total
0-14	53,700	17.8%
15-44	116,500	38.5%
45-64	80,800	26.7%
65-74	27,300	9.0%
75-84	17,700	5.9%
85+	6,500	2.1%
Total	302,500	100%

ONS, 2012a.

- 3.1.3 There are fewer men than women aged 75 and over, 14,400 women to 9,700 men. By 85 years and over this becomes a two-fold difference, 4,300 women to 2,100 men. This has implications for the design and uptake of services for older people (ONS, 2012a). See Appendix 2.
- 3.1.4 Demographics differ between Doncaster's Electoral Wards. Wheatley has the smallest proportion of people aged 65 and over (13.4%) while Torne Valley has the highest proportion (25.2%). These compare with a Doncaster average of 17%. In absolute numbers, Bessacarr & Cantley has the highest number aged 65 and over (3,105) while Central has the smallest (1,965). Essentially, older people are not distributed evenly across the Borough (DMBC, 2012). See Appendix 3 for the data on all 21 Wards.

3.2 Ethnicity

- 3.2.1 Ethnicity has a bearing on dementia. In Black & Minority Ethnic (BME) groups 6.1% of all diagnoses take the form of young onset dementia (<65yrs) compared with 2.2% for the UK population as a whole (The Alzheimer's Society, 2012). Factors such as stigma, awareness, service preference and workforce training can also influence diagnosis and uptake of services by minority groups.
- 3.2.2 Doncaster does not have an ethnically diverse population; 92% are White British compared with 86% for Yorkshire and Humber and 81% for England & Wales (ONS, 2012b). Of the ethnic groups in Doncaster, White Other forms the greatest proportion (3%). This is likely a result of migration from Eastern Europe since 2004. See Appendix 4.
- 3.2.3 The 2011 census recorded 587 Gypsy / Irish Travellers in Doncaster, though this is likely to be an undercount. Local estimates place the Gypsy / Irish Traveller population at 4,000 to 6000, constituting around 2% of the population depending on the time of year (Northern Housing Consortium, 2007; St Leger Homes, 2007). This is accepted to be one of the largest populations in the country.
- 3.2.4 Ethnicity projections to 2031 predict that all ethnic groups in Doncaster will grow. Most notably, the Asian / Asian British population will rise from 3,105 (1.1% of the population) to 5,177 (1.7%) (YHPHO, 2010). See Appendix 5.

3.3 Population projection

- 3.3.1 The number of people in Doncaster aged 65 and over may increase from 53,100 in 2012 to 73,400 in 2030 an increase of 30% (IPC, 2013a). As a proportion of the whole population, this equates to a rise from 18% to 24%. This rise is greater than that predicted at a national scale, meaning local services will face even greater demand from an ageing population. See Appendix 6.
- 3.3.2 Projected growth for those aged 85 and over is more dramatic locally and nationally. In Doncaster numbers may increase from 6,500 to 11,900 by 2030 a 63% rise. This equates to a rise from 2.4% to 4% of the overall population. See Appendix 7.

3.4 Social deprivation

- 3.4.1 Under the Indices of Multiple Deprivation 2010, Doncaster is ranked the 39th most deprived Local Authority out of 327 areas in England (DCLG, 2010). This places Doncaster in the 12% most deprived areas.
- 3.4.2 Deprivation varies within the Borough. Seven Wards fall into the most deprived quintile in England (the most deprived 1/5th); Adwick, Bentley, Central, Conisbrough & Denaby, Mexborough, Stainforth & Moorends, and Wheatley. These Wards contain 99,000 residents, 15,000 of which are aged 65 and over. No Doncaster Wards fall into the least deprived quintile though four are in the second least deprived; Edenthorpe, Kirk Sandall & Barnby Dun; Finningley; Sprotbrough; and Torne Valley. See Appendix 8 for full details.

3.5 Residential status and unpaid care

- 3.5.1 There may be 2,700 males aged 65-74 that live alone one in five males in this age category. This rises to 3,400 men aged 75 and over or one in three. A greater proportion of females live alone, 4,500 women aged 65-74 (one in three) and 8,906 women aged 75 and over (nearly two thirds) (IPC, 2013b). These people are less likely to receive informal care. See Appendix 9.
- 3.5.2 These estimates can be applied to the projections in section 3.3. By 2020 there may 7,174 men and 15,105 women aged 65 and over that live alone. See Appendix 9.
- 3.5.3 The Census recorded 33,150 people providing unpaid care in Doncaster, with 9,383 providing 50 or more hours per week. There are 7,301 unpaid carers over the age of 65 in Doncaster, or 14% of people in this age group. (ONS, 2013).
- 3.5.4 People providing unpaid care can experience poorer health; 7% of people providing no care report bad or very bad health, this compares with 14% of people providing 50 or more hours per week (ONS, 2013).
- 3.5.5 At the time of the census 197 residents were in Local Authority care homes, 734 residents were in nursing care homes and 977 residents were in non-nursing care homes (ONS, 2012c). See Appendix 10.
 - Priority Support for carers, especially those providing full time care and those carers experiencing poorer health themselves.

4 Epidemiology of dementia

4.1 Prevalence

- 4.1.1 Prevalence is the overall number of people with a condition at a single point in time. The NHS Commissioning Board Dementia Calculator predicts that there are 3,697 cases of dementia in Doncaster 83 with early onset dementia (<65yrs) and 3,614 with late onset dementia (NHSCB, 2013). See Appendix 11.
- 4.1.2 More males have young onset dementia than females (60% to 40%). In contrast, women form the majority of those with late onset dementia (65% to 35%)(NHSCB, 2013). See Appendix 12.
- 4.1.3 Projecting prevalence in line with population growth, by 2015 there may be 4,034 people living with dementia, a 9% increase (NHSCB, 2013). See Appendix 13.
- 4.1.4 Figures have been estimated for Electoral Wards based on the age and gender of the populations. The Wards with the highest number of cases are in the south and east of the Borough; Bessacarr & Cantley (266 cases), Torne Valley (209), Finningley (197) and Thorne (195). See Appendix 14 &15.
- 4.1.5 The picture is slightly different when looking at prevalence (the proportion of cases in the older population). Wards with the highest prevalence are more central; Bessacarr & Cantley (8.6% of people aged 65 years plus), Town Moor (7.9%) and Wheatley (7.8%). Prevalence is higher because these Wards have more people in the oldest categories (85 years and over), beyond which the likelihood of dementia rises sharply. See Appendix 14 &16.

4.2 <u>Incidence</u>

4.2.1 Incidence is a measure of the number of new cases occurring over a period of time. Applying estimates from the Medical Research Council (2005) to the local population structure, Doncaster might record around 990 new cases of late onset dementia each year. The gender split would be around 70:30 females to males. See Appendix 17.

4.3 <u>Diagnosis</u>

- 4.3.1 Stage of diagnosis is important. Early diagnosis benefits the patient and early intervention and support can also result in significant cost savings by delaying institutional care (Wimo & Prince, 2010).
- 4.3.2 The Dementia Calculator compares QOF registered patients against the estimated number of cases. In Doncaster there are estimated to be 3,697 cases, but only 2,001 patients were registered with GP practices in 2011/12. This provides a diagnosis rate of 54.1% and a diagnosis 'gap' of 1,696 people. See Appendix 18.

4.3.3 The Dementia Calculator makes a comparison between areas. Doncaster has the 34th best diagnosis rate out of 327 Local Authorities (in the highest 10% across England). Doncaster is also well placed against statistical neighbours, having the 3rd best rate of the 28 Manufacturing Towns. Sheffield, a geographic neighbour but not a statistical neighbour, has a particularly high diagnosis rate of 63.7%. See Appendix 19.

Priority – Increase diagnosis rates and diagnose people at an earlier stage.

4.4 Types of dementia

4.4.1 Dementia can take a number of different forms and causes. There are over 100 types of dementia, The Alzheimer's Society lists the main ones as;

Table 2 – Estimated number of cases by dementia type

Type of dementia	Percentage of all cases	Estimated number in Doncaster
Alzheimer's disease	62%	2292
Vascular dementia	17%	628
Mixed dementia	10%	370
Dementia with Lewy bodies	4%	148
Fronto-temporal dementia	2%	74
Parkinson's dementia	2%	74
Other dementias	3%	111

Knapp & Prince, 2007

- 4.4.2 Over half of cases have the Alzheimer's form of dementia, equating to 2,292 residents in Doncaster. Nearly 30% of cases have vascular dementia or a mixture of vascular and Alzheimer's dementia, equating to 998 residents.
- 4.4.3 A sizeable number of people have other types of dementia (407 cases, 11%) and it is important to consider other factors in people's lives, for instance;
 - People with Down syndrome are living longer and these people are more susceptible to early onset dementia (Kerr, 2009). Doncaster Advocacy work with 12 people with Down syndrome and dementia.
 - Trends in alcohol consumption may lead to an upsurge in alcoholrelated dementia (Gupta & Warner, 2008). Doncaster services are already noting this locally.

Priority – Support people with less common forms of dementia and related issues such as learning disabilities or alcohol.

Priority – Communicate the elevated risk of vascular dementia associated with high blood pressure, high cholesterol, smoking and diabetes. There is no treatment for vascular dementia so prevention is critical.

4.5 Severity of dementia

4.5.1 The Dementia Calculator details the severity of dementia in Doncaster. There are thought to be 2,034 mild cases and 1,203 moderate cases, which are more likely to reside in the community. There are around 460 severe cases of dementia, which are more likely to receive institutional care. See Table 3.

Table 3 – Estimated number of cases by dementia severity

Severity of dementia	% of all cases	Estimated cases in Doncaster
Mild	55%	2,034
Moderate	33%	1,203
Severe	12%	460

NHSCB, 2013

4.6 Living arrangements for people with dementia

- 4.6.1 Around two thirds of people with late onset dementia live in their own homes with the remaining third live in a care home (Knapp & Prince, 2007). As a result, Local Authorities with higher concentrations of care homes will have more residents with dementia.
- 4.6.2 In February 2012 there were 117 care home beds per 1,000 people aged 75 plus in Doncaster. This is comparable with the value for England (114 per 1,000) and places Doncaster in the middle of other Local Authorities (End of Life Care Intelligence Network, 2012).
- 4.6.3 The Dementia Calculator identifies 57 care homes in Doncaster providing 2,098 care beds, with assumed occupancy of 88%. On this basis, there are predicted to be 2,593 people with dementia living in the community and 1,104 people with dementia living in residential care. See Appendix 20.
- 4.6.4 The proportion of people entering care rises with age estimates increase from 27% for those aged 65-74 up to 61% for those over 90 (Knapp & Prince, 2007). This is understandable given a progressive severity of dementia as people age and a decline in informal support through bereavement.

5 Service utilisation

5.1 Primary Care

- 5.1.1 All practices in Doncaster can produce a register of patients diagnosed with dementia. As stated in section 4.3.3 2,001 residents are registered for dementia, equating to 54.1% of the estimated prevalence (NHSIC, 2013).
- 5.1.2 Within Doncaster, there is variation between GP practices. The lowest diagnosis rate is 27% and the highest 100% (NHSCB, 2013). Estimated prevalence at small geographic scales is less precise due to random variation so these rates should be treated with caution, but there may be opportunities to share learning between practices. See Appendix 22 for all GP practices.
- 5.1.3 Two QOF indicators relate to the care of dementia patients. DEM02 requires a practice to review the care of dementia patients in the preceding 15 months. Grouping all Doncaster GPs together, 1,419 out of 1,807 patients achieved this indicator, or 78.5% (NHSIC, 2013). This is comparable with England (79.3%). See Appendix 22 for practice level achievement.
- 5.1.4 Indicator DEM03 requires all newly diagnosed patients to have a series of tests (such as renal and liver function) 6 months before or after entering the register.
 237 new patients of the 282 achieved this indicator, or 84% (NHSIC, 2013). This is comparable with England (83.5%). See Appendix 23 for practice level achievement.

Priority – Reduce the disparity in diagnosis rates between GP practices.

5.2 Prescribing

- 5.2.1 NICE recommends four prescription drugs for Alzheimer's disease; galantamine, rivastigmine, donepezil and memantine (NICE, 2011). In Doncaster for 2011/12 there were 9,738 prescriptions for these drugs at a cost of over £650,000 (NHS Doncaster CCG, 2013a). Prescribing has increased year on year the number of items is up 65% and costs are up 50% since 2008/09. This increase is mirrored at a national level, suggesting wider influences. See Appendices 24 and 25.
- 5.2.2 The number of registered patients has increased over the same period by 42% (NHSIC, 2013) improved identification of patients explains some, but not all, of the increase in prescribing. See Appendix 26.
- 5.2.3 Anti-psychotic drugs were often prescribed to people with dementia. In 2009 the Department of Health prioritised a reduction in their use (DH, 2009b); people with dementia are at greater risk of side effects, symptoms may be the result of unmet need requiring a different solution, and antipsychotics have modest benefits for a short period of time (The Alzheimer's Society, 2013a).

Priority – Ensure the prescribing of dementia drugs meet NICE guidelines and continue the reduction in the use of antipsychotics.

5.3 Pharmacy services

- 5.3.1 A stakeholder consultation (summarised in section 6.2) identified a number of areas where pharmacy services can improve pathways and care in dementia, working in conjunction with GP practices.
- 5.3.2 Pharmacies could use Medicine Use Reviews to rationalise and simplify medicine regimes for people with dementia, which may increase adherence. Each pharmacy is commissioned to carry out 400 reviews per year (with half targeted at respiratory conditions, high risk drugs or people discharged from hospital).
- 5.3.3 There is also scope to improve the ordering of medicines establishing more repeat dispensing services so that GPs can issue 6 or 12 month prescriptions at a time. This would minimise problems incurred when a patient runs out of medicine and a new prescription is not in place.
- 5.3.4 Pharmacies are contracted to deliver six health promotion campaigns each year one of which could focus on dementia and target carers and families. Pharmacies could also play a greater role in screening for dementia and make referrals to the Memory Clinic. This would require clear communication to the person's GP, but it would minimise the number of services the patient passed through. Pharmacies see patients regularly and may be better placed to notice deteriorating memory.

Priority – Optimise the role of pharmacies in dementia pathways and care (awareness raising campaigns, reviewing and ordering medicines, screening for dementia and making direct referrals).

5.4 <u>Social Care</u>

- 5.4.1 327 residents aged 65 and over received social care for dementia in 2012/13 (DMBC, 2013a). This equates to 9% of the estimated prevalence and 16% of the cases known to NHS primary care.
- 5.4.2 Of these clients 57 received nursing care, 161 received residential care and 152 received community interventions. The clients receiving community care comprised home care (114), day care (76), professional support (3) and short term residential care (1) (DMBC, 2013a).
- 5.4.3 It has been predicted there are 1,104 people with dementia living in care homes (section 4.6.2). This is far higher than the 218 clients recorded in nursing and residential care. Some of this shortfall may be due to people purchasing private care. However, it is likely that there are people with undiagnosed dementia in care homes that are not designed to deliver dementia care.
- 5.4.3 Four residents received care for young onset dementia one recipient of community-based home care, two in residential care and one in nursing care (DMBC, 2013a). In May 2013 the RDaSH Young Onset Dementia Service was

- supporting 113 patients (section 5.6.8), suggesting there may be a shortfall in young clients with dementia accessing social care.
- 5.4.4 Of the people receiving community care for dementia, 96 have personalised the service they receive (63%) 72 with personalised home care, 34 with personalised day care, eight with direct payments and two through professional support (DMBC, 2013b).

Priority – Ensure people with dementia access social care where necessary.

There is a gap between social care clients and known NHS patients.

Priority – Identify people with dementia in care homes to ensure their setting meets their needs. There is a gap between the known and estimated numbers in residential care.

Priority – Promote personalised care for people with dementia and their carers.

5.5 <u>Telecare</u>

- 5.5.1 Unobtrusive sensors can be placed around the home that automatically raises an alarm if a problem is detected. These technologies can assist people to live independently and stay in their home for as long as possible. This telecare service costs £3.20 per week with no installation fee.
- 5.5.2 Telecare referrals are available for particular conditions. In Doncaster there were 173 referrals for dementia or Alzheimer's disease, and nine for medication prompts, in the 12 month period to January 2013 (prompts are usually provided for people with memory problems) (DMBC, 2013c). See Appendix 27.
- 5.5.3 Installations cannot be detailed by condition, though four solutions are of particular use to those with memory issues. Property exit sensors are the most frequent with 88 installations over the 12 month period, followed by seven flood detectors, three natural gas detectors and two medication reminders (DMBC, 2013c). See Appendix 28.
- 5.5.4 The number of referrals and installations are significantly below the estimated number of people with dementia living in the community there is scope to increase uptake, enhancing safety and peace of mind. The local telecare strategy aims to promote independent living and identifies dementia as a priority group (DMBC, 2011). See Appendix 29.
- 5.5.5 Telecare should be introduced as early as possible so people can adapt to the required routines. This becomes more difficult as the condition progresses.
- 5.5.6 Protocol within care homes is being developed. Doncaster MBC evaluated a pilot of telecare for people with dementia in residential establishments. Feedback identified a number of benefits; resident's maintained independence and dignity, families felt reassured, staff time was used more efficiently and units could retain residents for longer than usual. Of the 24 residents provided with telecare, 18 still had the devices after six months (75%).

Priority – Increase the uptake of telecare for people with dementia living in the community. This is most effective when introduced at an early stage.

5.6 Hospital admissions

- 5.6.1 152 residents of Doncaster were admitted to hospital with a primary diagnosis of dementia in 2012/13. Of these, 24% were admitted to mental health trusts and 76% to acute hospital trusts. This is a slight reduction on five years ago (2008/09) when 175 people were admitted (NHS Doncaster CCG, 2013b).
- 5.6.2 Many more people are admitted to hospital with dementia as a secondary diagnosis being admitted for a different reason but also having dementia. In 2012/13 a total of 2,386 people were admitted with a secondary diagnosis, 97% to acute hospital trusts (NHS Doncaster CCG, 2013a). This is an increase of 60% on five years ago (2008/09) when 1,456 people were admitted. Some of this increase will result from improved diagnosis rates, but there may also be a greater awareness of the signs and symptoms of dementia in hospital and an increased propensity to admit people from the community.
- 5.6.3 People with any diagnosis of dementia accounted for 2.7% of all admissions in 2012/13 given levels of under-diagnosis the true value is probably higher.
- 5.6.4 The primary diagnosis for people admitted with a secondary diagnosis of dementia is revealing. Many of these conditions are avoidable with appropriate community support, such as urinary and respiratory infections, pneumonia and falls. See Appendix 30 for the top 10 reasons for admission.
- 5.6.5 People with dementia spend longer in hospital. Bed occupation has been analysed as part of the evaluation of the RDaSH Hospital Liaison Team. Between February and October 2012, patients with dementia, delirium or depression spent 86% more days in hospital compared to patients without these conditions. There are signs that the liaison service is making an improvement; over the same period in 2011 these patients had 114% higher bed occupation (Chrisp et al, 2013).
- 5.6.6 The same report also details higher rates of readmission for dementia patients (a readmission is a return to hospital within 30 days of discharge for the original stay). These patients had 34% more readmissions than patients without these conditions. However reduced length of stay is not having a negative impact on readmissions, the equivalent rate in 2011 was 30% not statistically different.

5.7 Rotherham, Doncaster & South Humber (RDaSH) Mental Health Trust services

- 5.7.1 RDaSH services adopt a holistic approach based on need rather than working to a specific diagnosis. As a result the services respond to referrals for memory issues and do not require, or necessarily work towards, a diagnosis of dementia. The following data was obtained from paper based systems managed by each of the service areas.
- 5.7.2 In April 2013, RDaSH Memory Clinics were monitoring 695 patients who were receiving medication and had an Alzheimer's form of dementia.

- 5.7.3 Consultants saw 135 new patients with vascular forms of dementia in the 12 month period to April 2013. There are few options for the clinical treatment of vascular dementia, interventions are based on education and management of the condition to allow people to remain in their home and support for carers.
- 5.7.4 The Care Home Liaison Team provides support and advice to care homes across Doncaster, from basic residential settings to specialist residential EMI care (elderly mentally infirm). The liaison team received 537 referrals in the 12 month period to March 2013.
- 5.7.5 The Care Home Liaison Team also delivers dementia training to care homes. 103 members of staff in care homes received group education sessions in the 12 month period to March 2013 (in addition to on-going one to one training and support). Skills and knowledge in care homes is improving but there is still room for improvement.
- 5.7.6 The Hospital Liaison Team provides a similar service in Doncaster's acute hospital trust; advising on care practice, clinical decisions, discharge and post discharge care management. This is an essential function at any one time up to 25% of hospital beds are occupied by older people with dementia, and there is an unacceptable variation in the quality of dementia care in acute hospitals across England (The Alzheimer's Society, 2009).
- 5.7.7 The hospital team received 1,086 referrals in the 12 month period to March 2013. The team also delivered training to 194 members of hospital staff in group education sessions (in addition to on-going one to one training and support).
- 5.7.8 The hospital liaison service is a pilot, launched in January 2012, and underwent a recent evaluation by Chrisp et al (2013);
 - The service appears to have contributed to a reduction in falls by patients with dementia. Patients also experienced a reduction in length of stay without an adverse effect on readmissions.
 - Ward staff believe the liaison service improved the care of patients.
 However there was no impact on; ward staff's belief in their own ability to
 manage patients with mental health problems, ward staff's experience of
 work on the wards, or on perceived levels of cooperation and team
 working on the wards. It may take time for the liaison service to impact
 these perceptions.
 - To conclude, the service improved clinical outcomes and generated savings. Ward staff believe the service improved care but it may take longer for ward staff to feel more confident in themselves.
- 5.7.9 The Young Onset Dementia Service supports younger people who develop dementia before the age of 65 and their families providing assessment, counselling, on-going support and activities based on interests and previous work skills. The team received 127 referrals in the 12 month period to March 2013, the majority of these being from GPs (85%). In May 2013 the service was actively supporting 113 patients.

5.7.10 A post for a Primary Care Liaison Nurse has been funded for 18 months (beginning in April 2013). This role will promote early diagnosis of dementia, review processes and signpost to supports. The aim is to deliver the right assessment, treatment, review or support at an earlier stage, pre-empting demand on secondary care services. The nurse will visit all 44 Doncaster GP practices on a rolling programme.

5.8 The Alzheimer's Society services

- 5.8.1 The Alzheimer's Society in Doncaster supported 1,373 people in the 12 month period to March 2013. These comprised; 939 carers, family or friends; 399 people with late onset dementia; 11 people with young onset dementia; a small number of falling into other categories (The Alzheimer's Society, 2013b). See Appendix 31.
- 5.8.2 The service received 218 new referrals over the period around two thirds for carers (148 people) and one third for people with dementia (64 people). See Appendix 31.
- 5.8.3 Half of the referrals were self-directed (50%). The next most common referral sources were Community Psychiatric Nurses (13%), family members (13%) and social workers (10%). There were only three referrals from GPs over the period and none from hospital Consultants. Only one third sector organisation, Age UK, referred into the service. See Appendix 32.
- 5.8.4 Nearly 50% of new referrals (30 people) came from the DN4 and DN5 postcodes. Some postcode areas recorded few referrals (if any) despite a significant number of estimated cases; DN3 (Barnby Dun, Kirk Sandall & Edenthorpe), DN8 (Thorne & Moorends) and DN6 (Askern, Carcroft, Adwick le Street). Appendix 33.
- 5.8.5 The Alzheimer's Society runs dementia cafes in Conisbrough, Hatfield, Askern and Cantley. Average attendances range from 16 to 35 people per month. Signing for the Brain averages 13 attendances per month. The carers support group averages 20 attendances per month. Telephone supports average around 60 inbound and 60 outbound calls each month. See Appendix 34.
- 5.8.6 Uptake of these services is a fraction of estimated number of people with dementia and their carers. However, services could not meet a significant rise in demand within the current resources (Hopkinson, 2013).

Priority – Increase social prescribing whereby GPs refer to non-clinical services providing social, emotional or practical assistance. This requires support for the voluntary and community sector to accommodate any increase in demand.

5.9 Doncaster Dementia Forum

- 5.9.1 The Doncaster Dementia Forum meets once a month being held prior to the Carers Support Group and addressing the same audience. The Forum offers an opportunity for people with dementia, their carers and professionals to raise questions, concerns and wishes which may be resolved by the Forum or passed on to the Doncaster Dementia Alliance.
- 5.9.2 The Forum is also an informative session in contrast to the social nature of the Carers Support Group. People attending the session can access information on a variety of topics, for instance; advice on finance and benefits; services provided by the Council and third sector organisations; talks by hospital doctors; visits by local politicians; practical demonstrations such as chair based exercise, gardening and cookery.

5.10 Age UK services

- 5.10.1 Age UK are receiving more referrals from Memory Clinics as clients complete treatment and need to be referred on. Age UK can accommodate smaller numbers of people with dementia in mainstream services, which is beneficial for the person with dementia. However, rising demand means services are now being reshaped away from the needs of the original group (Ferres, 2013).
- 5.10.2 People are receiving earlier assessments but there is a gap once they receive a diagnosis. Commissioning plans need to do more to promote an active life for people in the early stages of dementia and their carers (Ferres, 2013).
- 5.10.3 Dementia pathways would benefit from a dedicated role embedded with GPs facilitating social prescribing, identifying gaps in service and providing coordination between primary care and acute hospital care (Ferres, 2013). In part this will fall into the remit of the Primary Care Liaison Nurse (section 5.7.10).
- 5.10.4 The Age UK service funded by Doncaster MBC is to be formalised from a grant to a contract, which will undergo a tendering exercise. As a result, Doncaster MBC will monitor people accessing the day service to inform a contract specification, ensuring service provision is based on current need.
- 5.10.5 Doncaster MBC have produced a briefing paper on support for Memory Services, acknowledging the need to create a broader peer support framework with improved networks, information and advice.

Priority – Develop better support for people diagnosed at an earlier stage.

5.11 End of life care for people with dementia

5.11.1 End of life care is defined as the last 12 months of life. Therefore services as part of the end of life pathway integrate with the final stages of dementia care. People with dementia may require episodes of hospital care resulting from their

- condition or due to their comorbidities, and will ideally be resettled into their home environment (private residence or nursing/care home).
- 5.11.2 Doncaster averages around 500 deaths per year with Alzheimer's disease, dementia or senility as an underlying or contributory cause (End of Life Care Intelligence Network, 2012). This is 17.5% of all deaths.
- 5.11.3 Of these dementia deaths, a high number occur in hospital compared to other similar areas (46% versus 35% in manufacturing towns), and a low number occur in care homes (43% versus 54% in manufacturing towns). The numbers dying at home (9%) and in hospices (0.2%) are similar to other areas (End of Life Care Intelligence Network, 2012).
- 5.11.4 None of the care homes in Doncaster have achieved the Gold Standard Framework for palliative care. This is significantly lower than the England figure of 1.6%, while some areas achieve as high as 15% (End of Life Care Intelligence Network, 2012).
- 5.11.5 A number of local priorities have been identified for end of life care in Doncaster. The following themes have been placed in ordered of importance;
 - Enhance District Nurse capability and capacity, including care at the end
 of life. A local project is reviewing these issues against national guidance
 such as Compassion in Practice (DH, 2012b). This work will be completed by
 March 2014.
 - Establish an Electronic Palliative Care Coordination System in Doncaster (EPaCCS, previously known as Locality Registers). This system would record an individual's preference for end of life care and allow this information to be accessed by the different providers involved.
 - Enhance the capacity and capability of nursing in care homes (linking to the above review of District Nursing). There is also a need to increase the propensity of GPs to attend care homes to tend to people at the end of life.
 - GPs are participating in the Find Your 1% campaign, identifying the
 estimated 1% of patients who should be receiving palliative advice and
 support. At present only 0.2% of Doncaster patients are on the palliative
 register (NHSIC, 2011/12). Improvements require a standardised palliative
 register including preferred place of death.
 - Review the model for specialist palliative acute care; joining up acute care, primary care, social care and care homes. Present arrangements under NHS Continuing Healthcare (whereby the NHS may fund social care for people nearing the end of life) can be inflexible.

Priority – Enhance the capacity and capability of District Nurses and nursing in care homes with regard to end of life care. Increase the propensity of GPs to attend care homes to tend to people at the end of life.

- 5.12 The cost of dementia in Doncaster
- 5.12.1 The annual cost of services used by people with late onset dementia has been estimated at:

Table 4 – Annual cost of services used by a person with late onset dementia

	Mild	Moderate	Severe	Residential care
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	2 0	O 2	O 2	£28,646
Total	£16,689	£25,877	£37,473	£31,296

Knapp & Prince, 2007

- 5.12.2 These figures date from 2005/06 these would be subject to inflation and service costs may have changed. However, applying these figures to the number of people known to services (patients registered with GPs and people receiving residential social care) provides a crude measure of cost.
- 5.12.3 The Dementia Calculator records 2,001 registered patients. Applying mild, moderate and severe proportions from Knapp & Prince (2007) provides local estimates of 1,101,640 and 260 respectively. If the 208 residents receiving social care accommodation were subtracted from the severe category (assuming those in accommodation will be severe cases), the 'known' costs would be in excess of £43 million per year. See Appendix 35.
- 5.12.4 These costs are likely to increase as Doncaster is predicted to have a larger, older population in the future. The Dementia Calculator predicts a 9% increase in dementia by 2015 (section 4.1.3), raising costs to £47 million per year.
- 5.12.5 A national report by the Alzheimer's Research Trust calculated the economic cost of dementia at £23 billion per year, to provide context this is more than cancer (£12 billion) and heart disease (£8 billion) combined (Luengo-Fernandez, Leal & Gray, 2010). The broad definition of cost included productivity loss due to mortality and absence from work (along with informal caregiving and expenditure on health and social care).

6 Service user and stakeholder voice

6.1 Summary

- 6.1.1 This section summarises three pieces of work specific to residents of Doncaster;
 - Two research papers on the experience of dementia diagnosis, which both arose from a sample of 20 carers in Doncaster,
 - Six stakeholder workshops to develop Dementia Friendly Communities in Doncaster.
 - A consultation event to capture the local understanding of dementia in Doncaster.

6.2 <u>Carer experience of diagnosis in Doncaster</u>

- 6.2.1 Two recent papers have been published describing the experience of patient diagnoses in Doncaster. Both arose from a sample of 20 carers for people with dementia. These detail the barriers that deter people from seeking help and the triggers and supports that encourage people to seek diagnosis.
- 6.2.2 Bounded autonomy in deciding to seek medical help: Carer role, the sick role and the case of dementia (Chrisp, Tabber & Thomas, 2013).

In most cases it was the carer that initiated contact with a healthcare professional, though this person's decision was bound in the actions of others;

There can be a contest over the decision to contact a healthcare professional, i.e. a fundamental disagreement about whether the person is un-well or not.

Social supports and social pressures affect people's decision to act. In many cases the carer was acting with the support of another person.

There may be disagreement even when there is a consensus that something is wrong - family members may question the right to act on another's behalf.

The ability of a person to impose the 'sick role' on another person depends on the clarity of the condition, sufficient evidence that symptoms are worsening, and the support of others to legitimise action.

6.2.3 Dementia early diagnosis: Triggers, supports and constraints affecting the decision to engage with the health care system (Chrisp et al., 2012).

On average it took over a year for a carer to talk to a friend or relative after noticing something was wrong with a loved one. It took a further 1.3 years to make contact with a healthcare professional. It then took 6 months to complete assessments and reach a formal diagnosis. The whole timeline spans 3 years and is dependent on a number of constraints, supports and triggers.

- Constraints e.g. fear of resistance from the person with dementia, family resistance or disagreement, co-morbidities that complicate or distract.
- Supports e.g. carer taking immediate action after confiding in a friend or relative, professionals noticing and highlighting the symptoms.
- Triggers e.g. crisis alerting people without doubt that something is wrong.
- 6.2.4 To conclude –the longest delay occurs prior to engagement with healthcare professionals. Diagnosis rates may improve by targeting family members and carers; increasing their knowledge of the symptoms, that these symptoms require a medical response, that it can be legitimate to contact a doctor on behalf of someone else. An All Party Parliamentary Group on Dementia reviewed the evidence on early diagnosis and provided extensive recommendations (*Unlocking Diagnosis*, All Party Parliamentary Group, 2012).
- 6.2.5 Note that these findings may not represent the whole population. The sample was entirely White British and largely comprised people living at home. The experience of minority groups and/or people in care homes may differ.
 - Priority Raise awareness and challenge preconceptions held by the public and patients. Communicate that symptoms warrant a medical response, that there are benefits to early diagnosis, that people can 'live well' with dementia.
- 6.3 <u>Summary of workshops to develop Dementia Friendly Communities in</u>
 Doncaster
- 6.3.1 AESOP Consortium was commissioned to help implement Dementia Friendly Communities in Doncaster, building on their work in York, *Dementia Without Walls* (Crampton, Dean & Eley, 2012).
- 6.3.2 The Consortium facilitated a process of stakeholder engagement to test Doncaster's dementia friendliness, full details are available in AESOP Consortium's summary report (2013). The process centred on the Four Cornerstones Model:
 - People how do carers, families, neighbours, health and social care professionals and the wider community respond to and support people with dementia?
 - Place how does the physical environment, housing, neighbourhood and transport support people with dementia?
 - Resources are there sufficient services and facilities for people with dementia and are these appropriate to their needs and supportive of their capabilities? How well can people use the ordinary resources of the community?
 - Networks do those who support people with dementia communicate, collaborate and plan together sufficiently well to provide the best support and to use people's own 'assets' well?

6.3.3 The process consisted of six workshops. An initial session scoped the project and identified successes and areas for improvement. This was followed by four workshops (one for each cornerstone) and final session to plan the next steps.

Table 5 – Stakeholder reflection on the current position in Doncaster

Good aspects making Doncaster dementia friendly	Areas for improvement
Once people are 'in' services, they	Access to services (diagnosis, referral and
receive a good service	the experience of service users)
RDaSH services are considered to be good	Scope to improve wider supports such as transport & housing
Alzheimer's Society Dementia Cafes are	The gap between prevalence and
successful	diagnosis
Good user involvement	The delay between first symptoms and referral to memory clinic
Good focus on positive living	Lack of public confidence that good
	treatment will be available
Focus on improving life after diagnosis	Choice
	Awareness of dementia and wider mental
	health issues in older age. Fear & stigma
	Lack of early support for carers

Table 6 - Observations drawn from the whole process;

Strengths	Areas for improvement	
The involvement and commitment of lead	The need to engage beyond health and	
partners, especially the CCG, RDaSH and	social care. The process did not	
DMBC. There is a perceived risk about	consistently engage with wider supports	
how this will transfer back into day-to-day	(e.g. environment, housing, planning,	
and long-term working relationships	leisure, community safety)	
The involvement and commitment of	A joined-up pathway creating a	
community partners, especially The	personalised path of support. There is a	
Alzheimer's Society, Age UK, Dementia	desire to personalise services, though an	
Forum, Doncaster CVS, SYCIL and Darts. It	element of competition between	
proved difficult to attract potential	providers means that people are	
partners such as the Chamber of	sometimes offered what is provided rather	
Commerce and small businesses.	than what they need.	
Openness, energy and willingness to	Working from a strategic position. More	
challenge. Healthy debate e.g. tensions	collaboration is required between	
between service providers or	organisations to achieve some goals, e.g.	
commissioners needing to consider the	helping people to remain in private	
whole system.	residence rather than residential care.	
Clarity about the way forward – identified	Political and senior leadership. Dementia	
links to mainstream strategies with support	is a HWB priority, an opportunity to sponsor	
from the Health & Wellbeing Board.	innovation but requiring commitment and	
	(re)investment from all Board members	

6.3.4 Stakeholders felt action plans arising from this work should link to the dementia strategy – early diagnosis and support, living well with dementia and support for carers. Of the three areas, the priority should be improvements to diagnosis, access to services, re-commissioning and market development.

Priority – Continue implementing Dementia Friendly Communities building on the work by AESOP Consortium.

- 6.4 The local understanding of dementia in Doncaster a consultation by darts
- 6.4.1 To make an area more dementia friendly, it is important to understand people's experience of dementia in wider society particularly those delivering day-to-day services. A consultation was carried out to address this gap.
- 6.4.2 Doncaster Community Art (darts) carried out a creative consultation on May 2nd 2013 at their accessible and central venue the Point. Around 80 people attended from a wide range of organisations and background. The event was facilitated by creative professionals rather than health professionals. Attendees were asked to reflect on their experience of encountering people (in their work place or elsewhere) who are confused, forgetful or lost without knowing the person's explicit dementia status. Photographs and artefacts that were part of the 'Collections' exhibition were used as a catalyst for discussion/data collection. For further details see the full report (darts, 2013)
- 6.4.3 Relevant stakeholders received an individual invitation alongside blanket marketing through websites, social media and newsletters. The event ran from 10.30am-6.30pm so that people could drop in before (a shift), during or after work. There was senior buy in from the contacted work places who gave staff permission (and time during their working day) to attend. However, some sectors were still absent from the event most notably transport and housing.
- 6.4.4 Themes emerged across the participants; these have been summarised below;

Training	People instinctively display patience and understanding when encountering someone with dementia, though many people expressed a need for specific dementia training within their organisation (rather than working 'on instinct'). Particular examples include the police service, the fire service, pharmacy services, care home staff, first aiders at the marketplace and the Frenchgate centre.
The changing behaviour of people with dementia	People acknowledged the behaviour of someone with dementia can make it hard to know the right course of action. The appearance/demeanour of a person with dementia had a bearing on their confidence to assist.
Taking time to assess someone with dementia	Several services talked about the difficulty of assessing someone with dementia, and how this needs to be done over a period of time due to changes in lucidity. People find it difficult to know they have done the right thing and fulfil a person's wishes when their capacity and decision making fluctuates.
Spotting the early signs of dementia	Many people had concerns about members of the public, work colleagues, or about family members. Most did not know how to approach the person but felt that early support would be helpful.
The needs of carers	Carers want support and information as a constant drip feed from the point of diagnosis and as the disease progresses. Some admitted to feeling no need for support at the initial diagnosis and later wished they had accepted support. The expertise of the carer is often overlooked by professionals.

6.4.5 Participant left post-it notes on a traffic light system to identify things that worked well and things that could be improved. These have been grouped and summarised below (green = good, amber = average, red = poor);

Transport	 Bus travel - drivers are impatient and lack understanding. Bus passes - it can be difficulty accessing bus passes on behalf of people with dementia. First Buses card that accompanies the bus pass to tell the driver a person has dementia. Shortage of wheelchair accessible taxis.
Partnership working	 A need for more joined up work between services and providers. Lack of a clear point of contact for referrals between partners. Adult social services can be resistant when asked to carry out assessments. Other services tend to 'pass the buck' to social services.
Social care services	 Home care call times can be inflexible. Day care services. Personal budgets. Telecare sensors and the Home Alarm Service.
Health services	 Touch screen systems in GP surgeries are inappropraite. GP receptionists lack confidentiality and can be rushed. Hospital mental health assessments can be rushed to free hospital beds. GP, NHS and Memory Clinics can be negative. The Memory Clinics 1st class. Community physiotherapy waiting lists are long. There is no support for people with vascular dementia. Pharmacies support many patients with dementia but could play a wider role. Pharmacies could help with screening and identify problems at an earlier stage. RDaSH community mental health teams provide a streamlined, accessible service.
Other services	 Sue Ryder befriending service. Doncaster Dementia Forum. Civic Office is not accessible for people with dementia. Utility services have pre-recorded messages that are unsuitable for people with dementia. Museums and art galleries have material to stimulate memories. Museums want to be involved more and acknowledge there is room to improve. Doncaster Culture & Leisure Trust has bespoke programmes and activity sessions but require more staff awareness at front line services.
Information	More leaflets and information for people to pick up themselves without having to ask for information.
Local shops	Safety in Doncaster (SID) – shops signing up to this, badges and key rings to say someone has dementia.

5.2.6 These findings contributed to drama events devised and performed by darts in May 2013. These were commissioned by NHS Doncaster CCG and Doncaster MBC, using local examples to raise awareness and challenge preconceptions.

Priority – Raise awareness and provide training for staff across all partner organisations (not limited to Health & Social Care) to make service more dementia friendly.

7. Appendices

7.1 NICE and SCIE guidance and standards

The National Institute for Health & Clinical Excellence (NICE) and the Social Care Institute for Excellence (SCIE) have produced a number of guidance documents and quality standards relating to dementia;

NICE resources

NICE Dementia Care Pathway;

http://pathways.nice.org.uk/pathways/dementia

NICE Quality Standard 1 – Dementia Quality Standard

http://publications.nice.org.uk/dementia-quality-standard-qs1

NICE Quality Standard 30 – Supporting People to Live Well with Dementia http://www.nice.org.uk/guidance/index.jsp?action=byID&o=14141

NICE Clinical Guideline CG42; Supporting people with dementia and their carers in health and social care

http://publications.nice.org.uk/dementia-cg42

NICE Technology Appraisal 217 - Donepezil, galantamine, rivastigmine and memantine for the treatment of Alzheimer's disease

http://publications.nice.org.uk/donepezil-galantamine-rivastigmine-and-memantine-for-the-treatment-of-alzheimers-disease-ta217

SCIE resources

SCIE Dementia Gateway (tips, tools and activities for people working in nursing, residential of domiciliary settings);

http://www.scie.org.uk/publications/dementia/index.asp

SCIE e-learning: The Open Dementia Programme;

http://www.scie.org.uk/publications/elearning/dementia/index.asp

SCIE Using ICT in activities with people with dementia

http://www.scie.org.uk/publications/ictfordementia/index.asp

Dementia and End of Life Care: Implications for people with sensory loss http://www.scie.org.uk/news/events/previousevents/files/dementia eol care event report.pdf

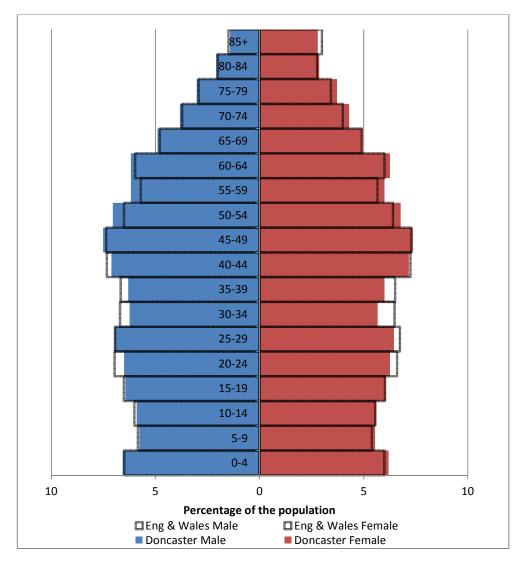
SCIE Research briefing 3: Aiding communication with people with dementia http://www.scie.org.uk/publications/briefings/briefing03/index.asp

SCIE research briefing 35: Black and minority ethnic people with dementia and their access to support services

http://www.scie.org.uk/publications/briefings/briefing35/index.asp

7.2 <u>Technical Annex</u>

Appendix 1 – Doncaster population pyramid.



Source - ONS, 2012a.

Appendix 2 – Doncaster population by age and gender.

Age		
Range	Male	Female
0-4	9,800	9,500
5-9	8,600	8,500
10-14	8,800	000,8
15-19	9,600	9,300
20-24	9,700	9,600
25-29	10,400	9,900
30-34	9,300	8,700
35-39	9,400	9,200
40-44	10,600	11,000
45-49	11,200	11,300
50-54	10,500	10,400
55-59	9,200	9,200
60-64	9,200	9,600
65-69	7,300	7,600
70-74	5,700	6,600
75-79	4,500	5,700
80-84	3,100	4,400
85+	2,100	4,300

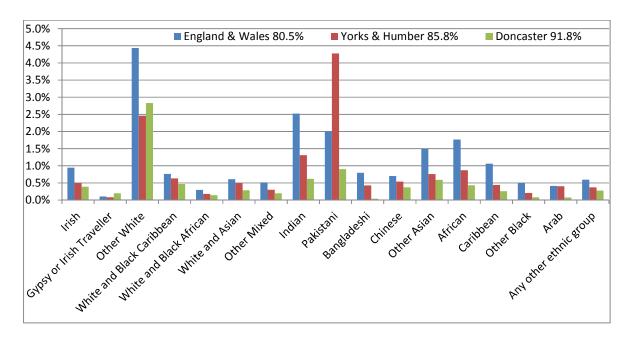
Source - ONS, 2012a.

Appendix 3 – Electoral Ward populations by broad age band.

Electoral Ward	Total	65-74yrs	75-84yrs	85+yrs	% 65+yrs
Adwick	15,671	1,180	761	343	14.6%
Armthorpe	14,144	1,281	816	335	17.2%
Askern Spa	13,026	1,335	895	307	19.5%
Balby	15,623	1,142	725	235	13.5%
Bentley	14,107	1,157	742	296	15.6%
Bessacarr & Cantley	14,302	1,394	1,166	546	21.7%
Central	18,405	1,033	675	257	10.7%
Conisbrough and Denaby	14,377	1,195	836	263	16.0%
Edenthorpe, Kirk S. etc	13,260	1,413	926	275	19.7%
Edlington & Warmsworth	13,393	1,296	807	226	17.4%
Finningley	15,233	1,648	964	338	19.4%
Great North Road	15,544	1,366	962	261	16.7%
Hatfield	13,307	1,400	823	295	18.9%
Mexborough	14,869	1,372	763	319	16.5%
Rossington	13,538	1,145	764	277	16.1%
Sprotbrough	11,731	1,398	856	259	21.4%
Stainforth & Moorends	13,795	1,206	730	212	15.6%
Thorne	16,456	1,533	953	337	17.2%
Torne Valley	12,073	1,632	1,042	364	25.2%
Town Moor	14,890	1,069	853	341	15.2%
Wheatley	14,753	1,016	645	315	13.4%
Doncaster total	302,500	27,208	17,704	6,400	17.0%

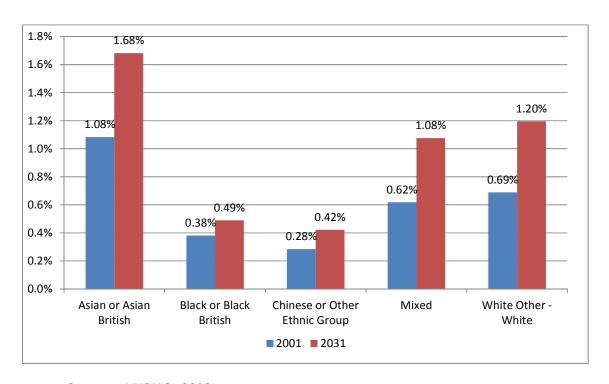
Source – DMBC, 2012. Calculated using the 2011 Census population And a download from the GP registration database.

Appendix 4 – Ethnicity of the Doncaster population.



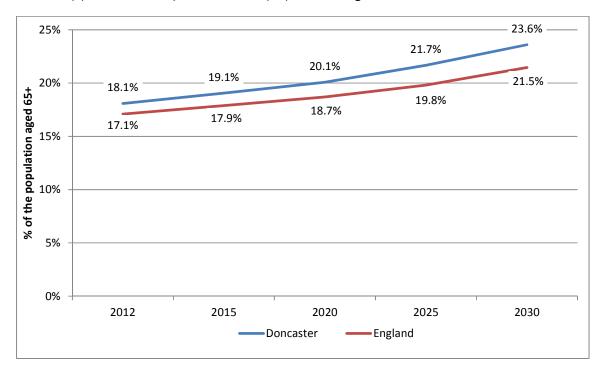
Source - ONS, 2012b.

Appendix 5 – Projection of ethnicity in Doncaster to 2031.



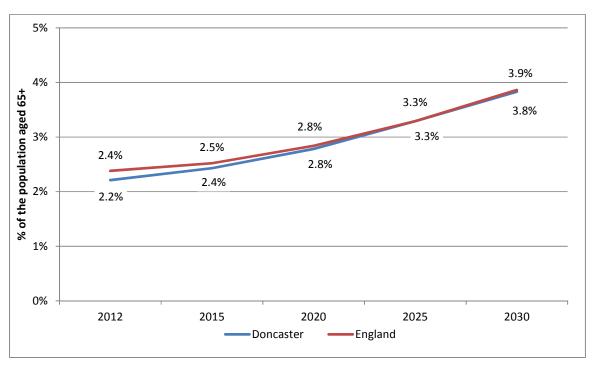
Source - YHPHO, 2010.

Appendix 6 – Projection of the population aged 65 and over to 2030.



Source - IPC, 2013a.

Appendix 7 – Projection of the population aged 85 and over to 2030.



Source - IPC, 2013a.

Appendix 8 – Rank of Electoral Wards in the national deprivation quintiles.

Least deprived quintile	2nd	3rd	4 th	Most deprived quintile
-	Edenthorpe Finningley Sprobrough Torne Valley	Bess. & Cantley Great North Road	Armthorpe Askern Spa Balby Edling. & Warms. Hatfield Rossington Thorne Town Moor	Adwick Bentley Central Conis. & Denaby Mexborough Stain. & M'ends Wheatley
-	52,185 residents 11,167 aged 65+	28,795 residents 5,720 aged 65+	110,309 residents 19,260 aged 65+	99,304 residents 15,353 aged 65+

Source - DCLG 2010 & ONS 2012a.

Appendix 9 – Doncaster residents estimated to live alone in 2012 & 2020.

	2012	
	Num. living	% of the
	alone	age group
Males aged 65-74	2,700	20%
Males aged 75 plus	3,400	34%
Females aged 65-74	4,500	30%
Females aged 75 plus	8,906	61%
	20:	20
	Num. living	% change
	alone	from 2012
Males aged 65-74	3,060	+13%
Males aged 75 plus	4,114	+21%
Females aged 65-74	5,040	+12%
Females aged 75 plus	10,065	+13%

Source - IPC, 2013b.

Appendix 10 – Doncaster residents in communal establishments.

	All		LA care		Nursing care		Non-nursing	
	establishr	ments	hom	nes	homes		care homes	
Doncaster	5,202	ı	197	3.8%	734	14.1%	977	18.8%
England & Wales	1,004,799	-	17,415	1.7%	149,834	14.9%	215,518	21.4%

Source - ONS, 2012c.

Appendix 11 – Estimated number of dementia cases in Doncaster.

	Estimated number
Early onset dementia	83
Late onset dementia	3,614
Total dementia	3,697

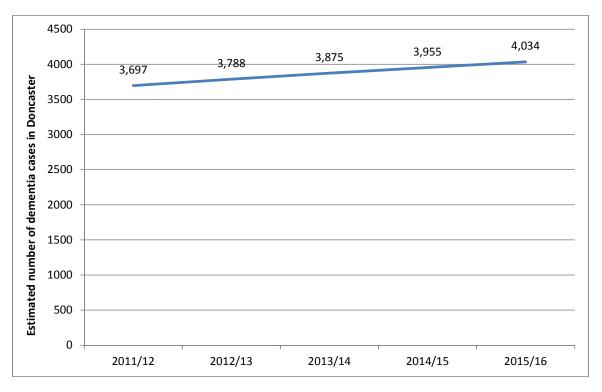
Source - NHSCB, 2013.

Appendix 12 – Estimated number of people with dementia by age and sex.

	Females	Males	Total
30-64	33	50	83
65-74	240	299	539
75-84	976	574	1,550
85+	1,123	447	1,570
Total	2,372	1,369	

Source - NHSCB 2013 (Dementia Calculator estimates by age and gender are only available in an unadjusted form and not match the total in Appendix 12.

Appendix 13 – Projected number of people with dementia in Doncaster to 2015/16.



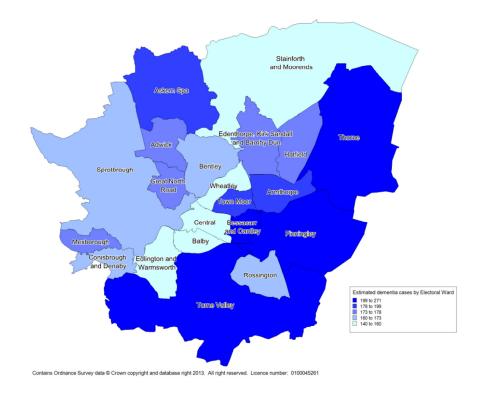
Source - NHSCB 2013.

Appendix 14 – Estimated number of dementia cases in each Electoral Ward.

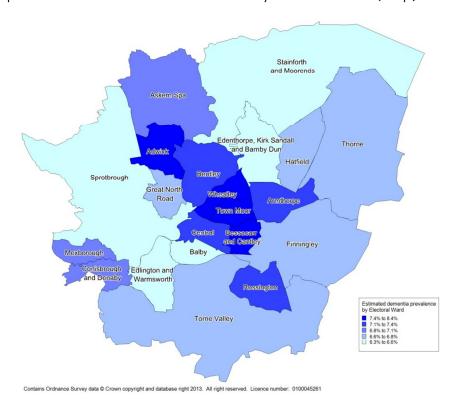
Grand Total	Early onset	Late onset	Total dementia cases	Pop 30+	% aged 30+	Pop 65+	% aged 65+
Adwick	4	172	176	9220	1.9%	2284	7.5%
Armthorpe	4	177	181	9003	2.0%	2432	7.3%
Askern Spa	4	176	180	8464	2.1%	2537	6.9%
Balby	4	139	143	9285	1.5%	2102	6.6%
Bentley	4	158	162	8498	1.9%	2195	7.2%
Bessacarr and Cantley	4	266	270	9571	2.8%	3105	8.6%
Central	4	140	144	10453	1.4%	1965	7.1%
Conisbrough and Denaby	4	160	164	8700	1.9%	2294	7.0%
Edenthorpe, Kirk S. and Barnby D.	4	172	176	9061	1.9%	2613	6.6%
Edlington and Warmsworth	4	151	155	8568	1.8%	2329	6.5%
Finningley	5	197	202	10214	2.0%	2950	6.7%
Great North Road	4	174	178	9715	1.8%	2589	6.7%
Hatfield	4	170	174	8553	2.0%	2518	6.8%
Mexborough	4	169	173	9182	1.9%	2454	6.9%
Rossington	4	157	160	8307	1.9%	2185	7.2%
Sprotbrough	4	163	166	8159	2.0%	2514	6.5%
Stainforth and Moorends	4	137	140	8176	1.7%	2148	6.4%
Thorne	4	195	199	10550	1.9%	2822	6.9%
Torne Valley	4	209	213	8648	2.5%	3037	6.9%
Town Moor	4	178	182	9068	2.0%	2263	7.9%
Wheatley	4	154	158	8765	1.8%	1976	7.8%

Source - Estimates from Knapp & Prince (2007) applied to the Census population (ONS, 2012).

Appendix 15 – Number of people with dementia by Electoral Ward (map).



Appendix 16 - Prevalence of dementia by Electoral Ward (map).



Appendix 17 – Estimated incidence of dementia in Doncaster per year.

	Male	Female	Total
65-69	50	48	98
70-74	83	40	123
75-79	64	84	148
80-84	53	137	190
85+	123	308	431
Total	373	618	990

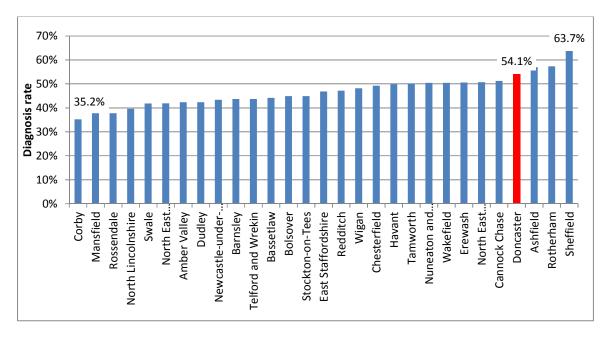
Source – Incidence rates from the Medical Research Council (2005) applied to the Census population (ONS, 2012a).

Appendix 18 – Diagnosis rate for dementia in Doncaster (2011/12).

Estimated number of cases	3,697
Patients on practice dementia registers	2,001
Diagnosis rate	54.1%
Diagnosis gap	1,696

Source - NHSCB 2013.

Appendix 19 – Diagnosis rates for ONS Manufacturing Towns and Sheffield City Council (2011/12).



Source - NHSCB 2013.

Appendix 20 – Estimate of people with dementia living in the community and living in care homes.

	Estimated cases in Doncaster			
	Community	Care Home		
30-34	1.7	-		
35-39	1.5	-		
40-44	3.1	-		
45-49	7.1	-		
50-54	12.7	-		
55-59	26.4	-		
60-64	30.9	-		
65-69	144.9	118		
70-74	265.0	110		
75-79	457.7	373		
80-84	680.6	3/3		
85-89	551.8	501		
90-94	342.9	501		
95+	67.1	112		
Total	2,593	1,104		

Source - NHSCB, 2013.

Appendix 21 – GP dementia diagnosis rates order low to high (2011/12).

Practice	Total list 2011	List 65yrs+	Expected cases	Registered cases	Diagnosis rate
Doncaster CCG	307762	52365	3706	1986	55.2%
C86018	11049	2149	158	42	26.6%
C86012	5521	1100	89	27	30.4%
C86032	6091	963	59	18	30.5%
C86609	2672	408	23	7	30.7%
C86034	6532	926	60	19	31.8%
C86026	4792	839	61	20	32.8%
C86030	1804	363	27	9	33.0%
C86024	9817	1672	114	38	33.3%
C86625	1858	250	15	5	33.4%
C86014	6572	900	67	23	34.3%
C86612	3445	574	34	12	35.0%
C86025	7921	1454	114	40	35.0%
C86606	1920	339	22	8	36.4%
C86605	9051	1484	98	37	37.9%
Y02635	2622	43	3	1	38.1%
C86006	9875	1736	127	50	39.3%
C86005	6200	1181	91	36	39.4%
C86009	8251	1558	101	41	40.6%
C86019	13653	2244	146	60	41.2%
C86021	6783	1257	88	40	45.6%
C86011	12526	1890	140	64	45.7%
C86022	9310	1400	109	50	45.7%
C86015	8691	1506	104	51	49.2%
C86017	9535	1547	115	57	49.4%
C86007	9838	1857	140	70	50.1%
C86029	15756	2522	195 94	101 54	51.7%
C86016 C86038	7299 8554	1381 1471	107	63	57.3% 58.9%
C86623	1978	288	18	11	59.9%
C86037	10386	1998	132	83	62.7%
C86626	2901	417	30	19	63.9%
C86020	9956	1680	128	83	64.9%
C86002	6312	1029	72	47	65.3%
C86039	5345	831	60	39	65.4%
C86001	10842	1932	137	90	65.7%
C86033	4410	504	29	20	68.8%
C86616	4365	707	51	36	70.4%
C86003	9688	1954	130	104	80.0%
C86013	9227	2369	168	136	81.0%
C86023	7060	1054	78	64	81.7%
C86613	3436	602	43	44	102.2%
C86614	4344	606	37	39	105.4%
C86611	5007	753	44	53	119.9%
C86621	4567	627	48	75	157.2%

Source - NHSCB, 2013.

Appendix 22 – GP achievement for QOF indicator DEM02 - review of patient care in the last 15 months (2011/12). Practice code in alphabetical order.

Number	Number eligible	
achieved	(excluding exceptions)	Achievement
1419	1807	78.5%
54	77	70.1%
29	44	65.9%
88	98	89.8%
25	33	75.8%
35	48	72.9%
47	61	77.0%
30	33	90.9%
37	60	61.7%
17	26	65.4%
119	120	99.2%
16	22	72.7%
31	46	67.4%
51	53	96.2%
40	51	78.4%
30	38	78.9%
34	53	64.2%
59	76	77.6%
		63.9%
		79.5%
		90.3%
		63.9%
		62.2%
		100.0%
		77.5%
	9	100.0%
11	14	78.6%
16	18	88.9%
11	17	64.7%
58	76	76.3%
		91.2%
21	32	65.6%
		86.1%
7	7	100.0%
		100.0%
		71.4%
		80.0%
		90.2%
		71.4%
		75.8%
		71.8%
		100.0%
		80.0%
		61.1%
		100.0%
	achieved 1419 54 29 88 25 35 47 30 37 17 119 16 31 51 40 30 34 59 23 35 56 23 23 20 69 9 11 16 11 58 52 21 31	achieved (excluding exceptions) 1419 1807 54 77 29 44 88 98 25 33 35 48 47 61 30 33 37 60 17 26 119 120 16 22 31 46 51 53 40 51 30 38 34 53 59 76 23 36 35 44 56 62 23 36 23 37 20 20 69 89 9 9 9 9 9 9 11 14 16 18 11 17 58 76 52 57

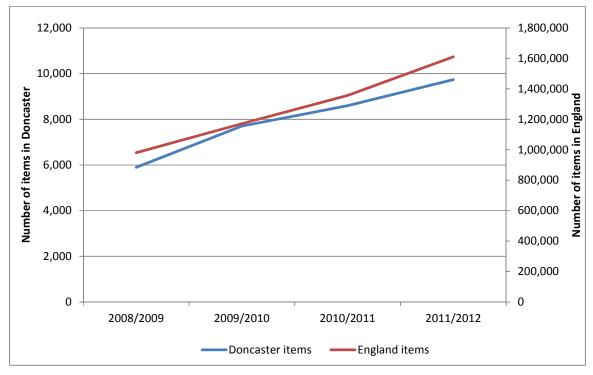
Source - NHSIC, 2013.

Appendix 23 – GP achievement for QOF indicator DEM03 – tests on newly registered patients (2011/12). Practice code in alphabetical order.

	Number	Number eligible	
Practice	achieved	(excluding exceptions)	Achievement
Doncaster CCG	237	282	84.0%
C86001	9	13	69.2%
C86002	7	11	63.6%
C86003	7	8	87.5%
C86005	5	7	71.4%
C86006	12	12	100.0%
C86007	12	14	85.7%
C86009	13	13	100.0%
C86011	6	10	60.0%
C86012	4	4	100.0%
C86013	14	14	100.0%
C86014	4	4	100.0%
C86015	5	7	71.4%
C86016	2	3	66.7%
C86017	3	3	100.0%
C86018	3	5	60.0%
C86019	8	10	80.0%
C86020	8	14	57.1%
C86021	3	4	75.0%
C86022	8	8	100.0%
C86023	9	9	100.0%
C86024	2	2	100.0%
C86025	2	2	100.0%
C86026	2	2	100.0%
C86029	14	21	66.7%
C86030	4	4	100.0%
C86032	2	2	100.0%
C86033	2	2	100.0%
C86034	2	2	100.0%
C86037	5	6	83.3%
C86038	14	14	100.0%
C86039	6	7	85.7%
C86605	9	9	100.0%
C86606	1	1	100.0%
C86609	0	1	0.0%
C86611	6	9	66.7%
C86612	2	2	100.0%
C86613	4	4	100.0%
C86614	4	4	100.0%
C86616	6	6	100.0%
C86621	6	7	85.7%
C86623	0	0	0.0%
C86625	2	2	100.0%
C86626	0	0	0.0%
Y02635	0	0	0.0%

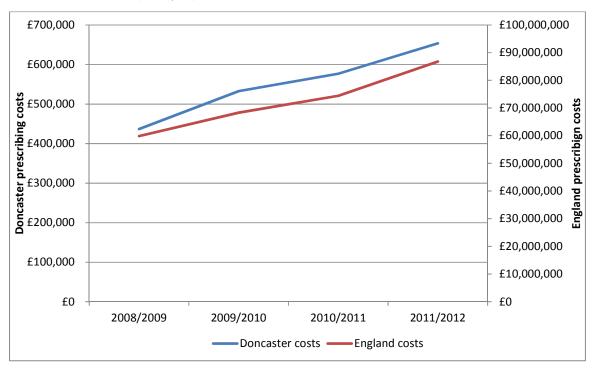
Source - NHSIC, 2013.

Appendix 24 – Number of items prescribed for galantamine, rivastigmine, donepezil and memantine (2011/12).



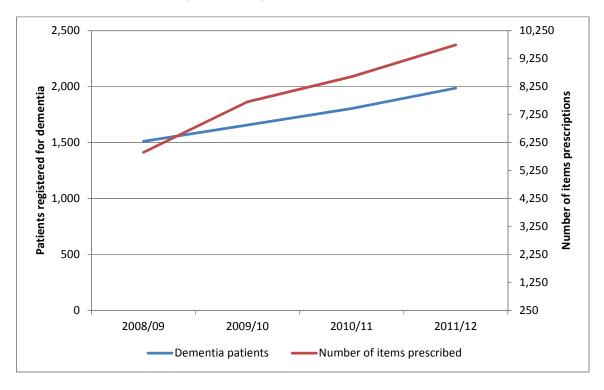
Source – NHS Doncaster CCG, 2013.

Appendix 25 – Cost of prescribing for galantamine, rivastigmine, donepezil and memantine (2011/12).



Source – NHS Doncaster CCG, 2013.

Appendix 26 – Comparison of trends in QOF registered patients and prescribing for dementia (2008/09 to 2011/12).



Source – NHS Doncaster CCG (2013) and NHS Information Centre (2013).

Appendix 27 – Telecare referrals in Doncaster by medical condition.

Referred Condition	Feb 2012	Mar 2012	Apr 2012	May 2012	Jun 2012	Jul 2012	Aug 2012	Sep 2012	Oct 2012	Nov 2012	Dec 2012	Jan 2013	Total
Alzheimer's	9	2	2	7	2	4	3	4	7	6	3	4	53
Dementia	9	11	9	8	8	21	11	2	14	19	6	2	120
Medication Prompts	1	1	1	1			1		1	2	1		9

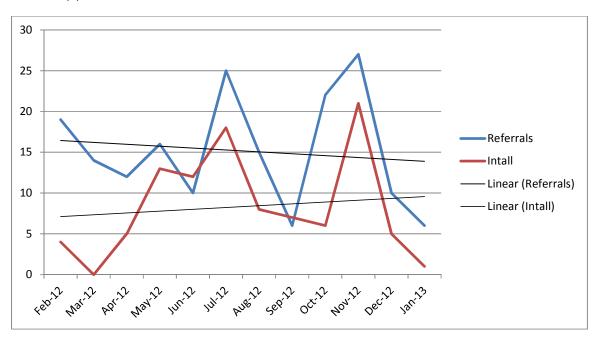
Source - DMBC, 2013b.

Appendix 28 – Telecare instillations in Doncaster.

Sensor installed	Feb 2012	Mar 2012	Apr 2012	May 2012	Jun 2012	Jul 2012	Aug 2012	Sep 2012	Oct 2012	Nov 2012	Dec 2012	Jan 2013	Total
Property Exit	2		5	12	10	16	7	7	6	18	5		88
Flood Detector	1			1		2				2		1	7
Natural Gas Detector					1		1			1			3
Memex Reminder	1				1								2

Source - DMBC, 2013b.

Appendix 29 – Trend lines for telecare referrals and installations in Doncaster.



Source - DMBC, 2013b.

Appendix 30 – Top 10 primary diagnoses for hospital admissions with a secondary diagnosis of dementia (2012/13).

Reason for admission	Count	% of total
Other disorders of urinary system	233	9.8%
Pneumonia, organism unspecified	194	8.1%
Fracture of femur	121	5.1%
Other symptoms and signs involving the nervous and musculoskeletal systems	88	3.7%
Unspecified acute lower respiratory infection	65	2.7%
Acute renal failure	58	2.4%
Other symptoms & signs involving cognitive functions and awareness	58	2.4%
Other soft tissue disorders, not elsewhere classified	50	2.1%
Other chronic obstructive pulmonary disease	49	2.1%
Pneumonitis due to solids and liquids	49	2.1%

Source - NHS Doncaster CCG, 2013.

Appendix 31 – New and existing clients for The Alzheimer's Society in Doncaster (February 2012 to January 2013).

	Count	Proportion
Total clients (new & existing)	1,373	
Younger people with dementia	11	0.8%
Older people with dementia	399	29.1%
Carers, former carers, family or friends	939	68.4%
Person with dementia of unknown age	3	0.2%
Other	23	1.7%
Total new referrals	218	
People with dementia	64	29.4%
Carers	148	67.9%
Other categories	6	2.8%
Gender of new referrals for people with dementia	64	
Male	31	48.4%
Female	33	51.6%
Ethnicity of new referrals	64	
White British	54	84%
Mixed background	8	12.5%
White Other	2	3.1%
Asian / Asian British	0	0.0%
Black / Black British	0	0.0%
Chinese or other SE Asian	0	0.0%

Source - The Alzheimer's Society, 2013.

Appendix 32 – Referral source into The Alzheimer's Society in Doncaster (February 2012 to January 2013).

Source of referral	Count	% of total
Self	103	50.2%
Family member	26	12.7%
CPN	26	12.7%
Social Services Care Team / Social Worker	21	10.2%
Memory Clinic	13	6.3%
Age UK	5	2.4%
Social Services- Assessment Direct	4	2.0%
GP	3	1.5%
Friend	2	1.0%
Other (specify)	2	1.0%
Consultant	0	0.0%
Total	205	

Source - The Alzheimer's Society, 2013.

Appendix 33 – Residence of people referred to The Alzheimer's Society (February 2012 to January 2013).

	1	
Postcode area	Referrals	General communities covered
DN1	2	Town Centre, Lower Wheatley
DN2	4	Wheatley Park, Wheatley Hills, Intake, Clay Lane, Town Moor, Bennetthorpe
DN3	6	Barnby Dun, Kirk Sandall, Edenthorpe
DN4	23	Bessacarr, Cantley, Balby, Hexthorpe, Warmsworth, Belle Vue, Hyde Park
DN5	7	Sprobrough, Harlington, Barnburgh, Hickleton, Scawsby, Scawthrope, Cusworth, Bentley, Toll Bar, Arksey
DN6	0	Campsall, Norton, Askern, Skellow, Carcroft, Adwick, Woodlands, Hampole, Highfield
DN7	3	Stainforth, Hatfield, Dunsville, Dunscroft, Hatfield Woodhouse
DN8	1	Thorne, Moorends
DN9	0	Auckley, Blaxton Finningley
DN10	0	Bawtry
DN12	6	Edlington, Conisbrough, Denaby
Unknown	12	-
Total	64	-

Source - The Alzheimer's Society, 2013.

Appendix 34 – Average monthly attendance for The Alzheimer's Society groups (February 2012 to January 2013). Balby Café and the Carers Education Group excluded as no data after March 2012.

	Conisborough Café	Hatfield Café *April 2012 To March 2013	Askern Cafe	Cantley Café	Doncaster Singing for the Brain	Carers Support Group	Doncaster Forum (Forestgate)	Home visits	Telephone support (outbound)	Telephone support (inbound)
Carers	14	9	12	19	7	11	11	4	58	64
People with dementia	12	7	11	16	6	9	9	4	50	04

Source - The Alzheimer's Society, 2013.

Appendix 35 – Estimated cost of dementia in Doncaster

	Mild	Moderate	Severe	Care home				
Estimated cases	1,101	640	52	208				
Cost	£16,689	£25,877	£37,473	£31,296				
Total	£18.4m	£16.6m	£2.0m	£6.5m				
	£43.4m							

Source – Estimates from Knapp & Prince (2007) applied to cases known to NHS primary care and adult social care.

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