



Public Health  
England

## **Improving the dementia diagnosis rate in North East England 2013**

An update on prevalence rates;  
diagnosis rates; crisis related hospital  
admissions.

## About Public Health England

Public Health England's mission is to protect and improve the nation's health and to address inequalities through working with national and local government, the NHS, industry and the voluntary and community sector. PHE is an operationally autonomous executive agency of the Department of Health.

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## Executive summary

The government published *Living Well with Dementia: A National Strategy* for England in 2009 in response to the need for a national strategic framework for making quality improvements to services for people with dementia and addressing health inequalities. Through the *Prime Minister's Dementia Challenge* NHS England in 2013 was able to quantify the first ever national ambition to improve the dementia diagnosis rates<sup>1</sup>. The aim is that by 2015 “two-thirds of people [with dementia] should have a diagnosis, with appropriate post diagnosis support”<sup>2</sup>.

The purpose of this paper is to provide further insight into issues affecting people with dementia living in the twelve local authority areas that constitute North East England, based on the most recent data sets available. In particular this report aims to -

- investigate the progress being made with objective 2 of the national strategy, in improving the rates of diagnosis for people with dementia
- quantify the changes in the rate of detection and diagnosis of people with dementia over a recent six-year period
- investigate the recent trends in the number of people being admitted to inpatient hospital facilities in an emergency situation where the primary diagnosis for the admission was recorded as dementia

## Findings

- dementia diagnosis rate in North East England (2012) was 51.0%, significantly higher than the England average of 45.2%. Rates across local authority areas in region range from 44.8% in Hartlepool to 62.4% in South Tyneside
- the recorded prevalence rate of dementia has increased in North East England by 35.8% over last six years (2006/07 to 2011/12), marginally higher than the national average. Recorded prevalence is significantly (one-fifth) higher in the region (618 individuals per 100,000 population) compared to the England average (529 per 100,000 population)
- all localities in North East England reported significant increases in the recorded prevalence of dementia over the six year period. Increases ranged from 13.7% in Newcastle to 59.9% in Hartlepool and increases in nine of the twelve localities were above the England average. Recorded prevalence of dementia for localities in North East England in 2011/12 range from 508 per 100,000 population in Middlesbrough to 814 in South Tyneside

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<sup>1</sup> The proportion of the estimated number of people with dementia who have a formal diagnosis.

<sup>2</sup> The Prime Minister's Dementia Challenge: Annual Report on progress 2013 (Page 4)

- in North East England the number of people being admitted to hospital as an emergency where the primary diagnosis was recorded as dementia has decreased by 34% between 2006/07 and 2011/12, reducing from 2.94 individuals per 1,000 population estimated with dementia aged 65 years & over, to a rate of 1.94
- decreases in the rates of admissions were reported in all localities ranging from 6% to 68%, except in North Tyneside with increases of 14%. The largest reductions in rates were in Redcar & Cleveland (68%) and Stockton (62%), with the rates in six of the twelve localities in 2011/12 being significantly lower than in 2006/07

### Increasing the dementia diagnosis rate

- in 2012, 51.0% of those with dementia have a diagnosis in North East England. Around 16,000 individuals estimated to have dementia resident in the region are yet to have a formal diagnosis. To achieve the two-thirds dementia diagnosis rate ambition set by NHS England around 5,300 more individuals with the condition need to receive a diagnosis and be offered support services
- by 2012 no locality in North East England has yet achieved the two-thirds dementia diagnosis rate, however good progress is being made in South Tyneside (62.4%), Gateshead (57.3%) and Darlington (56.6%)
- specialist memory services are a critical element in closing the dementia “diagnosis gap”. Further evaluation is required of their effectiveness and efficiency, along with analysis of their sources of referrals ensuring that the use of the service provision is optimised and equitable. Service capacity is also an important aspect of the pathway, ensuring that waiting times are reduced to a minimum. The publication of official incidence rates for cases of dementia would assist in planning the provision of memory services

### Improvements to date

- over the six-year period 2006/07 to 2011/12 there was a significant increase in the prevalence of individuals with a recorded diagnosis of dementia in North East England, rising by 35.8%
- over the six-year period 2006/07 to 2011/12 there were significantly fewer individuals with dementia being admitted to hospital in a crisis situation where the primary diagnosis was recorded as dementia, falling by 34%
- increases in the rate of recorded prevalence for dementia are evident in all the localities in North East England for the period 2006/07 to 2011/12. However the South Tyneside locality is most noteworthy and warrants further investigations to gather examples of good practice. In South Tyneside -
  - highest dementia diagnosis rate of 62.4% of all localities in North East England and within five percentage points of the NHS England two-thirds ambition
  - highest recorded prevalence rate (814 per 100,000 population) for dementia

- rate of detection and diagnosis of people living in the locality significantly increased by 51.2% during the period 2006/07 to 2011/12
- lowest rate in the region of emergency hospital admissions due to dementia of 1.30 people per 1,000 older population with dementia

## Introduction

The government published *Living Well with Dementia: A National Strategy*<sup>i</sup> for England in 2009 in response to the need for a national strategic framework for making quality improvements to services for people with dementia and addressing health inequalities. Objectives of the strategy include - increasing public and health workers awareness to dementia; improving the early diagnosis of people with dementia; providing access to good pathways of care; the provision of high quality information; improved support for those with dementia and their carers.

In 2012 the *Prime Minister's Dementia Challenge*<sup>ii</sup> re-affirmed ministerial support for the strategy and emphasized the need for the health and social care sector to do even more to make a real difference to the lives of people with dementia, their families and carers. In the 2013 progress report on the challenge<sup>iii</sup>, NHS England quantified the first ever national ambition to improve dementia diagnosis rates. The aim is that by 2015 “two-thirds of people [with dementia] should have a diagnosis, with appropriate post diagnosis support<sup>3</sup>”.

The purpose of this paper is to provide further insight into issues affecting people with dementia based on the most recent data sets available. This work provides part of the evidence base on dementia for health and social care professionals, policy makers and those with the responsibilities for commissioning services for people with dementia.

This paper includes an analysis of updated estimates and recorded prevalence of dementia which builds on the existing knowledge base of analysis and intelligence reports<sup>4</sup> that are already available covering the twelve local authority areas that constitute North East England. In particular this report aims to -

- investigate the progress being made with objective 2 of the national strategy, in improving the rates of diagnosis for people with dementia
- quantify the changes in the rate of detection and diagnosis of people with dementia over a recent six-year period
- investigate the recent trends in the number of people being admitted to inpatient hospital facilities in an emergency situation with the primary cause for the admission being the dementia

Appendix 1 contains a summary of the dementia statistics for each locality in North East England.

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<sup>3</sup> The Prime Minister's Dementia Challenge: Annual Report on progress 2013 (Page 4)

<sup>4</sup> Available via Public Health Intelligence North East website <http://www.phine.org.uk/social-care-north-east/resources#1838>

## Methodology

The purpose of the analysis of the dementia numbers was to provide a “current status” for North East England and its twelve constituent local authority areas, based on the latest available data. The purpose of the temporal analysis was to quantify the changes in recorded dementia since the publication of the *Dementia UK*<sup>iv</sup> report by the Alzheimer’s Society and investigate the progress being made with objective 2 of the national strategy, in improving the dementia diagnosis rates.

The data sources utilised in this study relating to the number of people with dementia were –

- estimated numbers with dementia – POPPI and PANSI<sup>v</sup> – Institute of Public Care at Oxford Brookes University – Crown copyright
- recorded numbers with dementia – Quality & Outcomes Framework<sup>vi</sup> – The Health & Social Care Information Centre – HSCIC copyright

The purpose of the analysis of the hospital episode statistics<sup>vii</sup> HES in this study was to identify the change in the pattern of inpatient admissions for those people being hospitalised because of their dementia in an emergency situation, as described in the NICE guidelines. It was assumed that the primary diagnosis code is used in cases where a crisis situation has arisen and that this code most likely reflects the main focus of the intervention received while in hospital i.e. resolving the immediate crisis situation.

For this study, all emergency hospital admissions across all specialities have been included where the primary diagnosis for the admission was recorded as dementia.

Memory services are an integral component in the diagnosis and care pathway of people with dementia and it was the intention to include in this report an analysis of the data for North East England. The original survey of the Establishment of Memory Services<sup>viii</sup> was undertaken in 2010/11 and after a review of the data source it was omitted because it was felt by the authors that memory service developments were likely to be quite dynamic and that the existing data set might present a distorted view of the current facts. The Royal College of Psychiatrists in collaboration with NHS England are currently undertaking a new audit of provision of memory clinics/services in England to provide an update on the findings of the 2011 audit. A report on the findings of the audit is to be published in October 2013. Further details can be obtained from the royal college website<sup>5</sup>.

Further details of the methodologies used in the production of this report can be found in the Appendix 2.

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<sup>5</sup> <http://www.rcpsych.ac.uk/workinpsychiatry/qualityimprovement/nationalclinicalaudits/memoryservicesaudit.aspx>

## Terms used in this study

- incidence rate of dementia – the rate of new cases of dementia arising in a population over a given period
- prevalence rate of dementia – the proportion of a population with dementia
- recorded prevalence of dementia – the proportion of a given population with a formal diagnosis of dementia included on a GP practice dementia register
- estimated prevalence of dementia – the proportion of a given population who are estimated to have dementia, irrespective of whether they have a formal diagnosis or not
- recorded numbers with dementia – an individual is included in the recorded figures for people with dementia if they have a formal diagnosis which is recorded on their GP practice dementia register
- estimated numbers with dementia – this is the number of individuals estimated to have dementia generated by the application of the age and gender specific prevalence estimates<sup>6</sup> to the population distribution for a locality
- dementia diagnosis rate – the proportion of the estimated number of people in a locality with dementia that have a formal diagnosis and are included on a GP practice dementia register
- hospital admission – admission to an inpatient facility due to an emergency situation where the primary diagnosis for the admission was recorded as dementia. An emergency admission is defined as one that is unpredicted and at short notice because of clinical need<sup>ix</sup>
- significant change in data trends – is the change between two periods of time that is a statistical/actual change in the data and not one due to random variation

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<sup>6</sup> Rates derived from the Dementia UK report (page xii)

# Findings

## Current numbers of individuals with dementia

In 2012 there was an estimated 32,500 residents of North East England with some form of dementia, representing an estimated all age prevalence of 1,248 per 100,000 population in the region. Those with dementia in North East England account for 5.0% of the national total of 650,000 and the prevalence among adults in the region is marginally above the national rate of 1,214 per 100,000 residents.

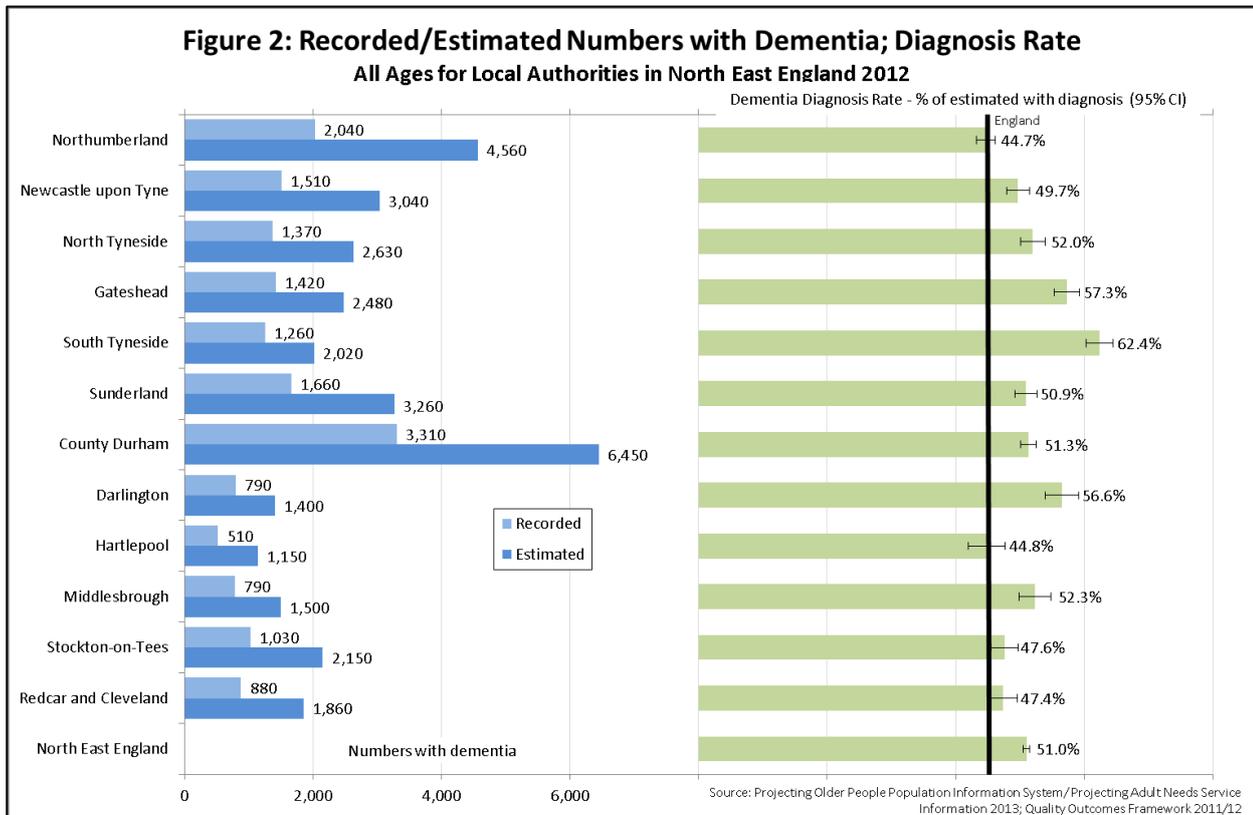
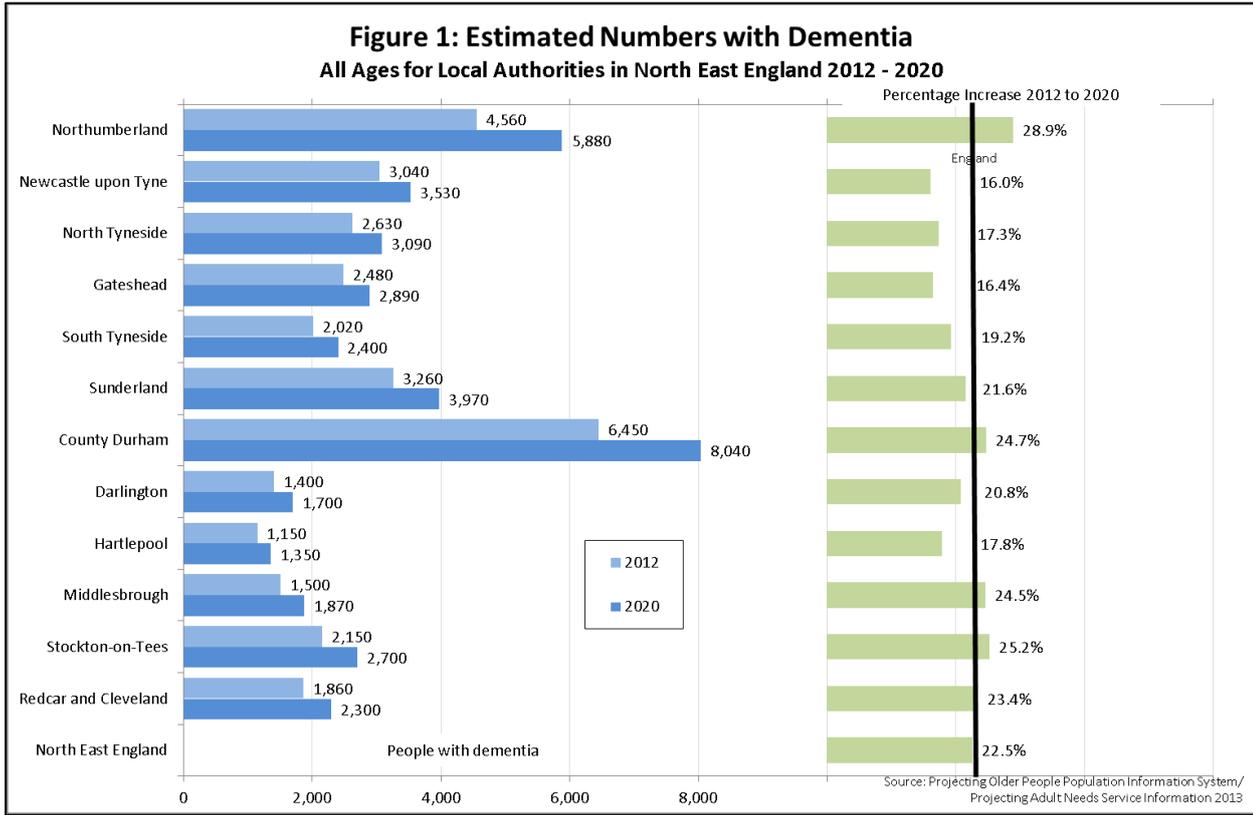
The largest estimates of people with dementia in North East England were resident in County Durham (6,450) and in Northumberland (4,560), reflecting the overall distribution of the population size and age structure within the region. Fewer individuals with dementia resided in Darlington (1,400) and Hartlepool (1,150) (Illustrated in Figure 1).

There were 16,500 individuals with a confirmed diagnosis of dementia resident in North East England in 2012. Recorded prevalence in the region, at 620.5 individuals per 100,000 population, is significantly higher than the rate for the whole of England (529.0). While the largest recorded number of people with dementia can be found in the localities of County Durham (3,310) and Northumberland (2,040), recorded prevalence is highest in South Tyneside (814) and Darlington (750). Prevalence rates in eight localities in the region were significantly higher than the rate for England, with the rates for Hartlepool, Middlesbrough, Newcastle and Stockton being statistically no different to national rate (Illustrated in Figures 2 & 3).

## Projected increase in numbers with dementia

Dementia is predominantly an age related condition and thus the numbers of people with dementia in North East England are likely to continue to increase as the number of older people in the region increase. Overall, between 2012 and 2020 the estimated number with dementia resident in North East England is projected to increase by 22.5% to 39,792, an increase of approximately 7,300 on the numbers in 2012. The growth in numbers in the region is below the expected increase in England of 23.2% (Illustrated in Figure 1).

The expected increase in numbers of people with dementia by area of residency in North East England ranges from 16.0% (Newcastle upon Tyne) to 28.9% (Northumberland). In five of the twelve local authority areas, there is an expected increase of greater than 23.2%, the national average for the period.



## The dementia diagnosis rate

In 2012 it was estimated that around 32,500 people with dementia are resident in North East England and around 51.0% have a formal diagnosis for their condition. The dementia diagnosis rate in the region is higher than the rate for England of 45.2%, as illustrated in Figure 2. However it is also estimated that around 16,000 individuals in the region have dementia, but as yet have no formal diagnosis.

Across North East England the dementia diagnosis rate ranges from 44.8% in Hartlepool to 62.4% in South Tyneside. The rate in all local authority areas is above the rate for England, except in Northumberland and Hartlepool.

## Changes in the recorded prevalence of dementia

Recorded prevalence of dementia in North East England increased by over one-third (35.2%) in the six-year period from 2006/07 to 2011/12, with the prevalence rate in the latter year of 618 individuals per 100,000 population. The recorded prevalence of dementia in the region increased at a rate marginally higher than the rate for England (33.5%) over the period and is one-fifth higher than the national rate of 529 per 100,000 population (Illustrated in Figure 3).

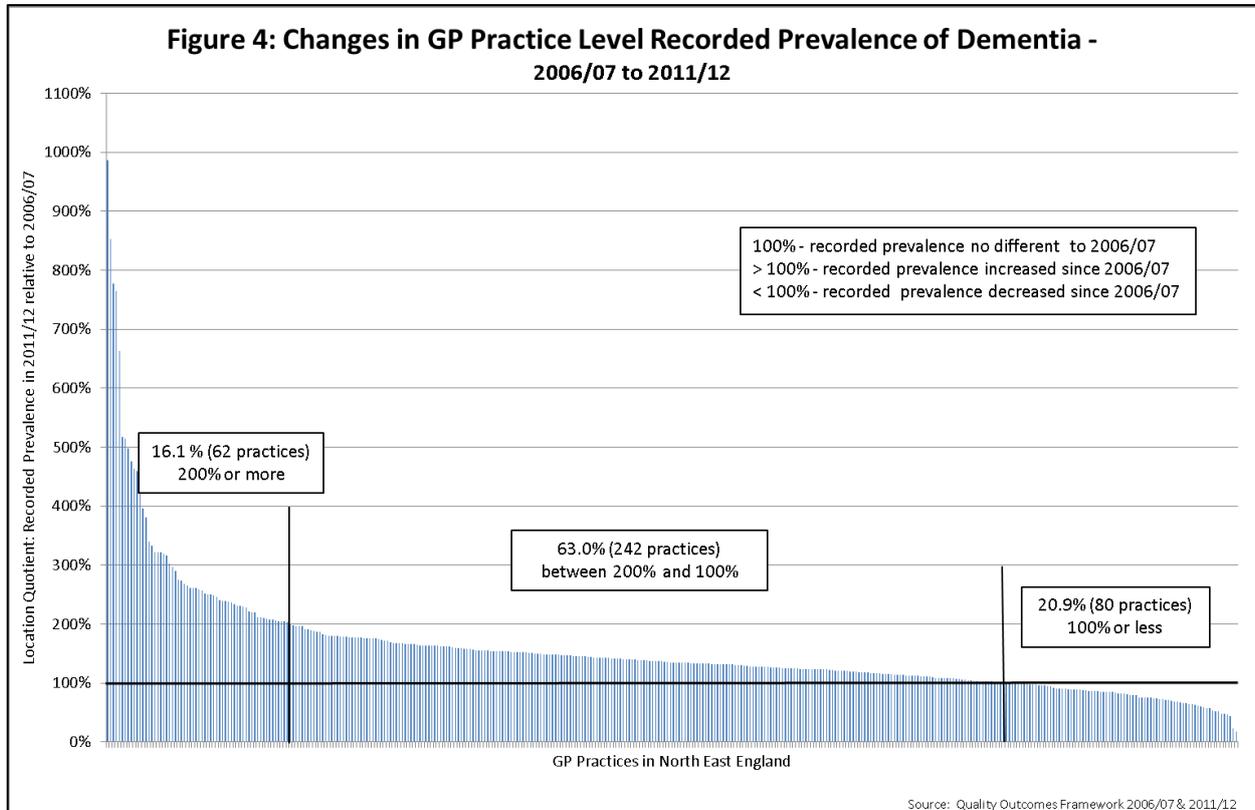
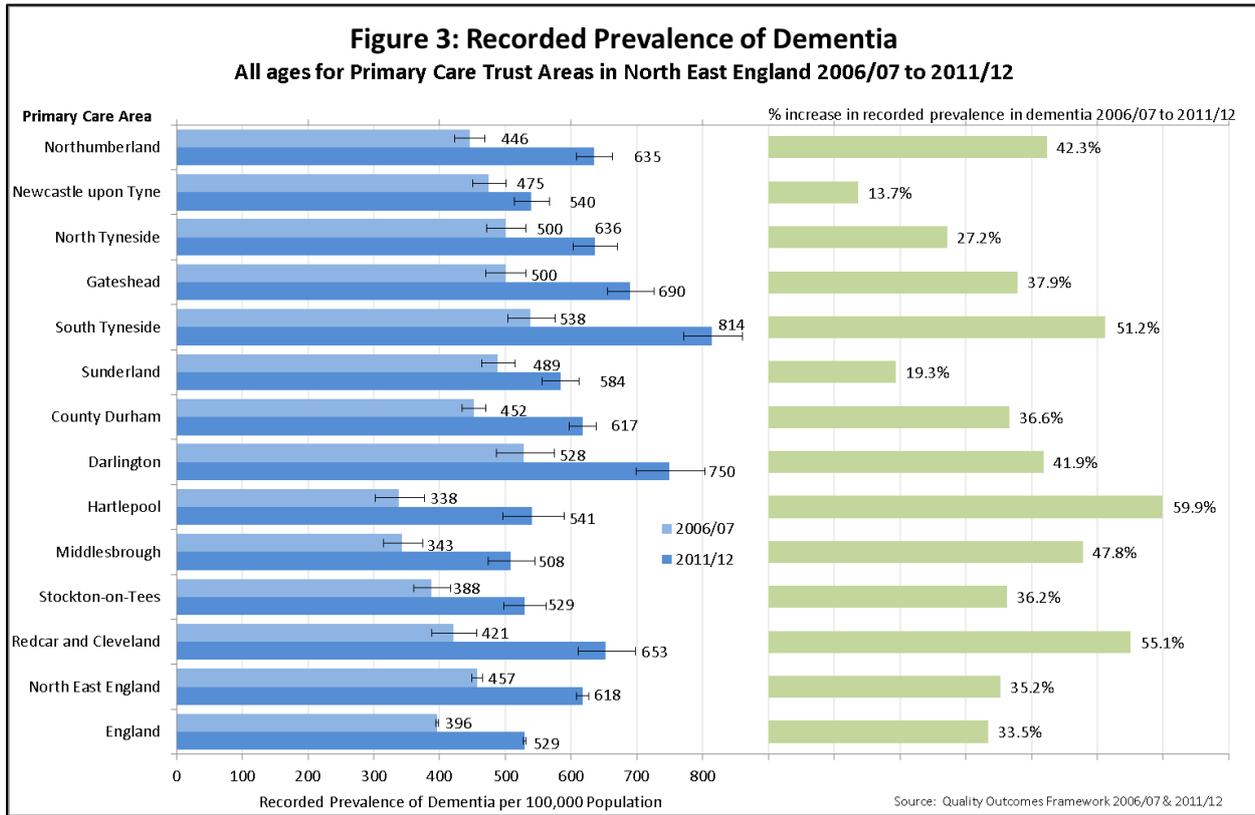
The recorded prevalence of dementia for localities in North East England in 2011/12 range from 508 per 100,000 population in Middlesbrough to 814 in South Tyneside. The individual rates for eight localities in the region are (statistically) significantly higher than the rate for England, with the rates for Hartlepool, Middlesbrough, Newcastle and Stockton being statistically no different to national rate.

All localities recorded significant increases in the recorded prevalence of dementia over the six year period, with increases ranging from 13.7% in Newcastle to 59.9% in Hartlepool. Increases in nine of the twelve localities were above the England average, with North Tyneside and Sunderland below the national rate.

Recorded prevalence for cases of dementia in 2011/12 was higher than in 2006/07 in 79.1% of GP practices across North East England, amounting to some 304 of 384 practices included in the study<sup>7</sup>. Recorded cases were more than doubled in 62 practices (16.1%), while fewer cases were reported in 80 practices (20.9%). Rates in 51 practices in the region were significantly higher in 2011/12 compared to 2006/07, with only two practices reporting recorded prevalence significantly lower (Illustrated in Figure 4).

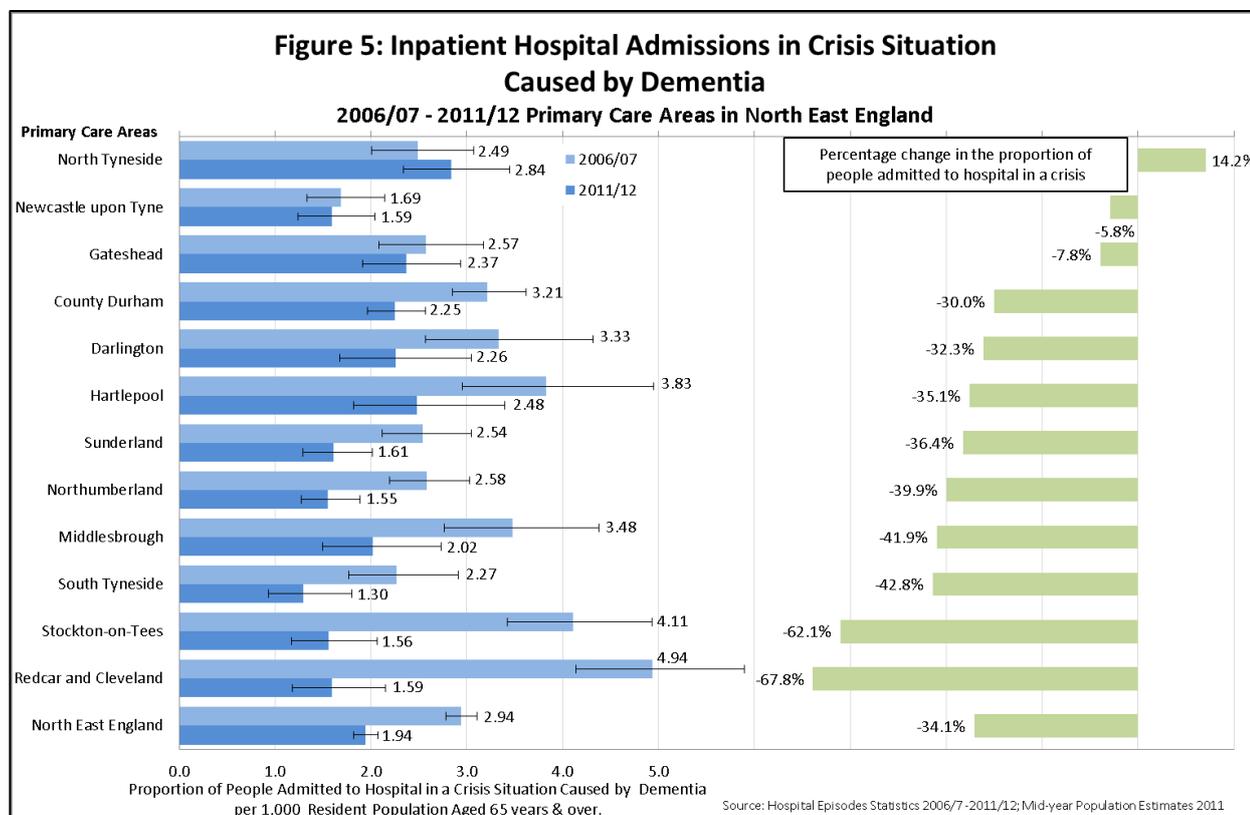
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<sup>7</sup> Detail contained in Appendix 2



## Hospital admissions in an emergency situation

Early detection and diagnosis of dementia should ensure that the occurrence of unpredictable situations caused by dementia and subsequent admissions to hospital are reduced to a minimum. Across North East England the number of people being admitted to hospital as an emergency where the primary diagnosis was recorded as dementia, has decreased by 34.1% between 2006/07 and 2011/12, reducing from 2.94 individuals per 1,000 population estimated with dementia aged 65 years & over, to a rate of 1.94. All primary care areas in the region recorded a fall in the rates of admissions ranging from 5.8% to 67.8%, except in North Tyneside where the rate of admissions increased by 14.2%. The largest reductions in rates were in Redcar & Cleveland and Stockton (62.1%), with the rates for a total of six localities in 2011/12 being significantly lower than in 2006/07. The lowest rate of admissions in 2011/12 was in South Tyneside (1.30 individuals per 1,000 aged 65 years & over estimated with dementia) while in North Tyneside the rate was the highest (2.84) (Illustrated in Figure 5).



## Discussion

The aim of the national dementia strategy published by the national government in 2009 was to put into motion work on the 17 key objectives that would improve the care of people with dementia. Objective 2 of the strategy was to improve the early detection of people with dementia, so the individuals concerned, their family and carers could access the relevant services to plan and implement future care provision, thus maintaining a good quality of life for all concerned.

### Increasing the dementia diagnosis rate

The ambition of NHS England is that by 2015 two-thirds of people estimated to have dementia should have a diagnosis, with appropriate post diagnosis support. Evidence provided in this report illustrates that there has been a significant increase in the recorded prevalence of dementia across the localities of North East England during the period 2006/7 to 2011/12, bringing the rates more into line with the estimated numbers. However there still exists a “diagnosis gap” between the current dementia diagnosis rates within the region and the two-thirds ambition. It is estimated that around 16,000 individuals with dementia who are resident in North East England, are yet to have a formal diagnosis for the condition. To achieve the two-thirds ambition set by NHS England, around 5,300 more residents of the region with dementia need to be diagnosed and offered support services.

While the target date set by NHS England was for 2015, at present (2012) no locality in North East England has yet achieved the ambition of two-thirds dementia diagnosis rate, however good progress is being made in South Tyneside (62.4%), Gateshead (57.3%) and Darlington (56.6%).

As the diagnosis rate approaches the two-thirds ambition, closing the “diagnosis gap” further will become more difficult and alternative methods of identification might be required to detect the less obvious of cases. In the national dementia strategy the case was presented for the development of local specialist memory services to provide diagnosis and support for people with dementia. Whilst it would be critical to get the right capacity and specification for the memory service provision to meet the local demand for a diagnosis, it would be equally critical to ensure that service referrers had the skills and competencies to identify the likely symptoms of dementia and know the referral procedures. A number of the objectives in the national strategy address these issues, but an analysis of the referral patterns to the memory services would identify the further educational needs of referrers, that if addressed would maximise the opportunities for people with dementia to get a prompt and accurate diagnosis for their condition and enable them access the most appropriate support services.

## Improvements to-date in the early detection and diagnosis of dementia

The dementia “diagnosis gap” has been a known issue for a number of years. However through the local implementation of the national strategy in North East England and along with national awareness campaigns, there has clearly been an improvement in the rates of detection and diagnosis.

Over the six-year period 2006/07 to 2011/12 there was a significant increase in the prevalence of individuals with a recorded diagnosis of dementia in North East England, rising by 35.8%. The increase in the recorded prevalence in the region during the period exceeded the projected increase of the estimated prevalence (8.1%) of dementia for the same period. The increases in recorded dementia are therefore not only down to increases in the estimated prevalence, but also down to some systemic improvement in the detection and diagnosis people with dementia. While further research is required into what has actually caused the increases in rates i.e. “what works”, it is likely that the implementation to-date of the national strategy in the region has made a substantial contribution. It is likely that there is a greater level of awareness of the symptoms of dementia among both clinicians and the general public than there was in 2006 and that the provision of local memory services has also assisted the process.

In the national dementia strategy, evidence was presented in the case for change that stated too few people with dementia receive an early formal diagnosis. In fact, diagnoses are often made too late for choices to be made and that the diagnoses are made at a time of crisis<sup>8</sup>. A desirable consequence of the improvements in early detection and diagnosis of dementia may therefore be fewer individuals being admitted to hospital in a crisis situation. While there is no proof of causal link between the two sets of events, during the same period of the increases in recorded prevalence in North East England (2006/07 to 2011/12), there has also been a significant reduction of over one-third in the rate of older people with dementia being admitted to hospital because of their dementia in a crisis situation.

Increases in the rate of recorded prevalence for dementia are evident in all the localities in North East England for the period 2006/07 to 2011/12. South Tyneside currently has the highest recorded prevalence rate (814 per 100,000 population) for dementia in the region. In recent years the rate of detection and diagnosis of people living in the locality has significantly increased (by 51.2%) and South Tyneside now has the highest dementia diagnosis rate (62.4%) of all localities in North East England. South Tyneside currently also has the lowest rate of emergency hospital admissions to inpatient facilities among older people for the treatment of dementia (1.30 people per 1,000 older population).

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<sup>8</sup> Living Well with Dementia: A National Strategy (page 34)

## Conclusions

By assuming that interaction with the health system is beneficial and desirable for people with dementia, then overall progress is being made in North East England towards the implementation of the early diagnosis objective in the national dementia strategy. However further research is required to assess the efficiency and the effectiveness of the health system and to evaluate the sustainability of the current approaches to support people with dementia.

The recorded prevalence of dementia i.e. those with a diagnosis, has increased significantly in all localities within the region over the recent period, with the resultant “diagnosis gap” falling across all areas. While as at 2012, no locality in North East England has yet reached the NHS England ambition of two-thirds of people with dementia having a diagnosis, the evidence does suggest that significant progress has been made and the target is realistically achievable by 2015.

Fewer people are having the experience of being admitted to hospital in a crisis situation where the primary diagnosis for the admission was recorded as dementia. Rates of admissions have fallen recently by around one-third suggesting that more people with dementia are able to access community and primary care services, minimising crisis situations. However further investigations are required into the patterns of use of the inpatient facilities, to ensure that their use is minimised and the provision of community services meets the potential demand of people with dementia and their carers.

Alternative and innovative approaches may be also required to finally close the “diagnosis gap” as it may become progressively harder to detect and diagnose the majority of those still without a diagnosis. The provision of memory services across North East England is likely to be contributing to these improvements in the dementia diagnosis rates. However further research is required to assess if there is sufficient capacity in the memory services to meet the demand of users, or whether the services are as efficient and effective as expected.

Evidence presented in this report suggests that a number of the approaches being taken in localities in North East England are worth further investigation as potential examples of good practice. South Tyneside is one locality that stands out. The recent improvements in the detection and diagnosis have increased the dementia diagnosis rate for the locality to within five percentage points of the NHS England two-thirds ambition, while reducing the rate of hospital admissions for crisis resolution related to dementia.

A hindrance to the current planning of early diagnosis and support services for people with dementia is the lack of official and robust data being published on the incidence of dementia. Data included in this report examines the prevalence of dementia, that is the stock of people of people with dementia. This data should be supplemented with the number of new cases (incidence) of dementia including attributes of diagnosis type and stage on the condition. Without such data the efficiency of services for people with dementia cannot be holistically planned and evaluated. For example waiting times for access to memory services may vary considerably from locality to locality.

This report only investigated the hospital admissions for those people being admitted in an emergency situation due to their dementia. Further work is also required to investigate the approaches employed in secondary care in relation to the detection and onward referral to specialist services of people with dementia, who are admitted to hospital for the treatment of non-dementia related conditions. This work should also include the analysis of the additional support received while an inpatient and the impact this has on the length of stay in hospital.

## Appendix 1: Dementia in numbers for North East England

### North East England

- 51.0% dementia diagnosis rate in 2012, therefore 49.0% of individuals with dementia lack a formal diagnosis, some 16,000 individuals.
- 32,500 individuals estimated to have dementia in 2012.
- 16,500 individuals with a diagnosis of dementia, amounting to a prevalence of 618 per 100,000 population in 2012.
- 9.1% increase in the estimated numbers of individuals with dementia between 2007 and 2012.
- 35.8% increase in the number of recorded cases with a diagnosis of dementia between 2006/07 and 2011/12.
- 22.5% predicted increase in the numbers with dementia by 2020, amounting to an increase of 7,000 individuals.
- 1.94 individuals per 100,000 older people with dementia are admitted to hospital where the primary diagnosis of the admission was recorded as dementia, 34.1% lower than in 2006/07.

### County Durham

- 51.3% dementia diagnosis rate in 2012, therefore 48.7% of individuals with dementia lack a formal diagnosis, some 3,100 individuals.
- 6,450 individuals estimated to have dementia in 2012.
- 3,310 individuals with a diagnosis of dementia, amounting to a prevalence of 617 per 100,000 population in 2012.
- 10.8% increase in the estimated numbers of individuals with dementia between 2007 and 2012.
- 36.6% increase in the number of recorded cases with a diagnosis of dementia between 2006/07 and 2011/12.
- 24.7% predicted increase in the numbers with dementia by 2020, amounting to an increase of 1,500 individuals.
- 2.25 individuals per 100,000 older people with dementia are admitted to hospital where the primary diagnosis of the admission was recorded as dementia, 30.0% lower than in 2006/07.

#### Darlington

- 56.6% dementia diagnosis rate in 2012, therefore 43.4% of individuals with dementia lack a formal diagnosis, some 1,300 individuals.
- 1,400 individuals estimated to have dementia in 2012.
- 790 individuals with a diagnosis of dementia, amounting to a prevalence of 750 per 100,000 population in 2012.
- 11.9% increase in the estimated numbers of individuals with dementia between 2007 and 2012.
- 41.9% increase in the number of recorded cases with a diagnosis of dementia between 2006/07 and 2011/12.
- 20.8% predicted increase in the numbers with dementia by 2020, amounting to an increase of 300 individuals.
- 2.26 individuals per 100,000 older people with dementia are admitted to hospital where the primary diagnosis of the admission was recorded as dementia, 32.3% lower than in 2006/07.

#### Gateshead

- 57.3% dementia diagnosis rate in 2012, therefore 42.7% of individuals with dementia lack a formal diagnosis, some 1,000 individuals.
- 2,480 individuals estimated to have dementia in 2012.
- 1,420 individuals with a diagnosis of dementia, amounting to a prevalence of 690 per 100,000 population in 2012.
- 6.1% increase in the estimated numbers of individuals with dementia between 2007 and 2012.
- 37.9% increase in the number of recorded cases with a diagnosis of dementia between 2006/07 and 2011/12.
- 16.4% predicted increase in the numbers with dementia by 2020, amounting to an increase of 400 individuals.
- 2.37 individuals per 100,000 older people with dementia are admitted to where the primary diagnosis of the admission was recorded as dementia, 7.8% lower than in 2006/07.

#### Hartlepool

- 44.8% dementia diagnosis rate in 2012, therefore 55.2% of individuals with dementia lack a formal diagnosis, some 650 individuals.
- 1,150 individuals estimated to have dementia in 2012.
- 510 individuals with a diagnosis of dementia, amounting to a prevalence of 541 per 100,000 population in 2012.
- 16.7% increase in the estimated numbers of individuals with dementia between 2007 and 2012.
- 59.9% increase in the number of recorded cases with a diagnosis of dementia between 2006/07 and 2011/12.
- 17.8% predicted increase in the numbers with dementia by 2020, amounting to an increase of 200 individuals.
- 2.48 individuals per 100,000 older people with dementia are admitted to hospital where the primary diagnosis of the admission was recorded as dementia, 35.1% lower than in 2006/07.

#### Middlesbrough

- 52.3% dementia diagnosis rate in 2012, therefore 47.7% of individuals with dementia lack a formal diagnosis, some 730 individuals.
- 1,500 individuals estimated to have dementia in 2012.
- 790 individuals with a diagnosis of dementia, amounting to a prevalence of 508 per 100,000 population in 2012.
- 5.6% increase in the estimated numbers of individuals with dementia between 2007 and 2012.
- 47.8% increase in the number of recorded cases with a diagnosis of dementia between 2006/07 and 2011/12.
- 24.5% predicted increase in the numbers with dementia by 2020, amounting to an increase of 370 individuals.
- 2.02 individuals per 100,000 older people with dementia are admitted to hospital where the primary diagnosis of the admission was recorded as dementia, 41.9% lower than in 2006/07.

#### Newcastle upon Tyne

- 49.7% dementia diagnosis rate in 2012, therefore 50.3% of individuals with dementia lack a formal diagnosis, some 1,550 individuals.
- 3,040 individuals estimated to have dementia in 2012.
- 1,510 individuals with a diagnosis of dementia, amounting to a prevalence of 540 per 100,000 population in 2012.
- 3.0% increase in the estimated numbers of individuals with dementia between 2007 and 2012.
- 13.7% increase in the number of recorded cases with a diagnosis of dementia between 2006/07 and 2011/12.
- 16.0% predicted increase in the numbers with dementia by 2020, amounting to an increase of 500 individuals.
- 1.59 individuals per 100,000 older people with dementia are admitted to hospital where the primary diagnosis of the admission was recorded as dementia, 5.8% lower than in 2006/07.

#### North Tyneside

- 52.0% dementia diagnosis rate in 2012, therefore 48.0% of individuals with dementia lack a formal diagnosis, some 1,300 individuals.
- 2,630 individuals estimated to have dementia in 2012.
- 1,370 individuals with a diagnosis of dementia, amounting to a prevalence of 637 per 100,000 population in 2012.
- 5.7% increase in the estimated numbers of individuals with dementia between 2007 and 2012.
- 27.2% increase in the number of recorded cases with a diagnosis of dementia between 2006/07 and 2011/12.
- 17.3% predicted increase in the numbers with dementia by 2020, amounting to an increase of 450 individuals.
- 2.84 individuals per 100,000 older people with dementia are admitted to hospital where the primary diagnosis of the admission was recorded as dementia, 14.2% higher than in 2006/07.

#### Northumberland

- 44.7% dementia diagnosis rate in 2012, therefore 55.3% of individuals with dementia lack a formal diagnosis, some 2,500 individuals.
- 4,560 individuals estimated to have dementia in 2012.
- 2,040 individuals with a diagnosis of dementia, amounting to a prevalence of 635 per 100,000 population in 2012.
- 12.7% increase in the estimated numbers of individuals with dementia between 2007 and 2012.
- 42.3% increase in the number of recorded cases with a diagnosis of dementia between 2006/07 and 2011/12.
- 28.9% predicted increase in the numbers with dementia by 2020, amounting to an increase of 1,300 individuals.
- 1.55 individuals per 100,000 older people with dementia are admitted to hospital where the primary diagnosis of the admission was recorded as dementia, 39.9% lower than in 2006/07.

#### Redcar & Cleveland

- 47.4% dementia diagnosis rate in 2012, therefore 52.6% of individuals with dementia lack a formal diagnosis, some 1,000 individuals.
- 1,860 individuals estimated to have dementia in 2012.
- 880 individuals with a diagnosis of dementia, amounting to a prevalence of 653 per 100,000 population in 2012.
- 11.1% increase in the estimated numbers of individuals with dementia between 2007 and 2012.
- 55.1% increase in the number of recorded cases with a diagnosis of dementia between 2006/07 and 2011/12.
- 23.4% predicted increase in the numbers with dementia by 2020, amounting to an increase of 450 individuals.
- 1.59 individuals per 100,000 older people with dementia are admitted to hospital where the primary diagnosis of the admission was recorded as dementia, 67.8% lower than in 2006/07.

#### South Tyneside

- 62.4% dementia diagnosis rate in 2012, therefore 37.6% of individuals with dementia lack a formal diagnosis, some 750 individuals.
- 2,020 individuals estimated to have dementia in 2012.
- 1,260 individuals with a diagnosis of dementia, amounting to a prevalence of 814 per 100,000 population in 2012.
- 4.8% increase in the estimated numbers of individuals with dementia between 2007 and 2012.
- 51.2% increase in the number of recorded cases with a diagnosis of dementia between 2006/07 and 2011/12.
- 19.2% predicted increase in the numbers with dementia by 2020, amounting to an increase of 400 individuals.
- 1.30 individuals per 100,000 older people with dementia are admitted to hospital where the primary diagnosis of the admission was recorded as dementia, 42.8% lower than in 2006/07.

#### Stockton-On-Tees

- 47.6% dementia diagnosis rate in 2012, therefore 52.4% of individuals with dementia lack a formal diagnosis, some 1,100 individuals.
- 2,150 individuals estimated to have dementia in 2012.
- 1,030 individuals with a diagnosis of dementia, amounting to a prevalence of 529 per 100,000 population in 2012.
- 16.2% increase in the estimated numbers of individuals with dementia between 2007 and 2012.
- 36.2% increase in the number of recorded cases with a diagnosis of dementia between 2006/07 and 2011/12.
- 25.2% predicted increase in the numbers with dementia by 2020, amounting to an increase of 550 individuals.
- 1.56 individuals per 100,000 older people with dementia are admitted to hospital where the primary diagnosis of the admission was recorded as dementia, 62.1% lower than in 2006/07.

#### Sunderland

- 50.9% dementia diagnosis rate in 2012, therefore 49.1% of individuals with dementia lack a formal diagnosis, some 1,600 individuals.
- 3,260 individuals estimated to have dementia in 2012.
- 1,660 individuals with a diagnosis of dementia, amounting to a prevalence of 584 per 100,000 population in 2012.
- 8.9% increase in the estimated numbers of individuals with dementia between 2007 and 2012.
- 19.3% increase in the number of recorded cases with a diagnosis of dementia between 2006/07 and 2011/12.
- 21.6% predicted increase in the numbers with dementia by 2020, amounting to an increase of 700 individuals.
- 1.61 individuals per 100,000 older people with dementia are admitted to hospital where the primary diagnosis of the admission was recorded as dementia, 36.4% lower than in 2006/07.

## Appendix 2: Project methodologies

### Dementia prevalence

The purpose of the analysis of the dementia numbers (Figure 1 & Figure 2) was to provide a “current status” for North East England and its twelve constituent local authority areas, based on the latest available data. The purpose of the temporal analysis (Figure 3 & Figure 4) was to quantify the changes in recorded dementia since the publication of the *Dementia UK* report by the Alzheimer’s Society and investigate the progress being made with objective 2 of the national strategy, in improving the dementia diagnosis rates.

The data sources utilised in this study relating to the number of people with dementia were –

- estimated numbers with dementia – POPPI and PANSI – Institute of Public Care at Oxford Brookes University – Crown copyright
- recorded numbers with dementia – Quality & Outcomes Framework – The Health & Social Care Information Centre – HSCIC copyright

The all age population dementia prevalence rates have utilised the following population estimates –

- recorded prevalence of dementia – practice list population which consists of the count of all individuals registered with a particular GP in the financial year. Data sourced from the Quality & Outcomes Framework outputs from Health & Social Care Information Centre
- estimated prevalence of dementia – general 2012 mid-year population estimates generated by the Office for National Statistics<sup>x</sup> – Crown copyright

The dementia diagnosis rate (Figure 2) has been derived using the ratio of the recorded number with a diagnosis of dementia on a practice register (QOF data) and the estimated number with dementia (POPPI and PANSI) for a given PCT/local authority area. The 95% confidence intervals for the primary care areas are calculated using the Wilson method<sup>xi</sup>.

The change in recorded prevalence for primary care areas (Figure 3) is calculated by the ratio of data for 2006/07 and 2011/12. The recorded prevalence for practices (Figure 4) uses the same methodology as for primary care areas where the data is available for both periods for the practice. Twenty practices from 2011/12 list omitted due to no data in 2006/07 and 16 practices from 2006/07 list omitted due to no data in 2011/12. The 95% confidence intervals for the primary care areas are calculated using the Wilson method.

## Hospital admissions

The purpose of the analysis of the hospital episode statistics (HES) in this study was to identify the change in the pattern of inpatient admissions for those people being hospitalised because of their dementia in an emergency situation, as described in the NICE guidelines. It was assumed that the primary diagnosis code is used in cases where a crisis situation has arisen and that this code most likely reflects the main focus of the intervention received while in hospital i.e. resolving the immediate crisis situation. However this does not constitute a formal diagnosis for dementia.

People with dementia should be cared for in a community setting as far as possible. Early detection and diagnosis will enable individuals with dementia to access services that will reduce the need for inpatient admissions. Inpatient admissions should only be considered necessary if the person is - severely disturbed and needs to be contained for his or her own health and safety and/or the safety of others; an assessment in a community setting is not possible, for example if there are complex physical and psychiatric problems<sup>xii</sup>.

For this study, all emergency hospital admissions across all specialities have been included and the admissions of people with dementia have been categorised generally into three types. These are -

- admissions due to an emergency situation where the primary diagnosis for the admission was recorded as dementia
- admissions for physical or psychiatric reasons unrelated to dementia, where the individual has a known prior diagnosis for dementia
- admissions for physical or psychiatric reasons unrelated to dementia, where the individual has no known diagnosis for dementia

Only the first group of admissions have been analysed in this report.

Cases are included in this data set when the primary diagnosis for the hospital episode of care includes one of the following International Classification of Diseases 10<sup>xiii</sup> (ICD10) codes –

- F00 - Dementia in Alzheimer's disease
- F01 - Vascular dementia
- F02 - Dementia in other diseases classified elsewhere
- F03 - Unspecified dementia
- F04 - Organic amnesic syndrome not induced by alcohol or other psychoactive substances
- G30 - Alzheimer's disease
- G31 - Other degenerative diseases of nervous system not elsewhere classified

The count of the people admitted to hospital in an emergency situation is derived from the number of unique patient identifiers with a first admission episode (FAE) in the financial year for the above ICD10 codes recorded in the primary diagnosis field. The

inpatient hospital admission rate for the treatment of dementia is then defined as the count, with the denominator being the number of people estimated to have dementia in the locality. The 95% confidence intervals are calculated using the Wilson method.

# Authors, acknowledgements & references

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