About this publication

This publication takes information from a variety of sources to provide a compendium of statistics about dementia in England.

It provides both new analysis and previously published statistics. New analysis includes linked mental health and mortality data, and longitudinally linked hospital data.

The publication aims to be of interest to a range of audiences, including policy makers, commissioners, researchers, patients and carers.

The publication looks at five aspects of dementia care broadly aligned to national strategic aims:

• Preventing well
• Diagnosing well
• Supporting well
• Living well
• Dementia and mortality
Introduction

What is dementia?¹

Dementia is a common condition. Your risk of developing dementia increases as you get older, and the condition most frequently occurs in people over the age of 65.

Dementia is a syndrome (a group of related symptoms) associated with an ongoing decline of the brain and its abilities. This includes problems with:

- memory loss
- thinking speed
- mental agility
- language
- understanding
- judgement

Dementia is an umbrella term that describes a group of symptoms that are caused by many diseases that affect the brain, for example: Alzheimer's disease and vascular disease.

¹ Source: NHS Choices
www.nhs.uk/conditions/dementia-guide/pages/about-dementia.aspx
What is dementia?¹

People with dementia can become apathetic or uninterested in their usual activities, and have problems controlling their emotions. They may also find social situations challenging, lose interest in socialising, and aspects of their personality may change.

A person with dementia may lose empathy (understanding and compassion), they may see or hear things that other people do not (hallucinations), or they may make false claims or statements.

As dementia affects a person's mental abilities, they may find planning and organising difficult. Maintaining their independence may also become a problem. A person with dementia will therefore usually need help from friends or relatives, including help with decision making.

Most types of dementia can't be cured, but if it is detected early there are ways you can slow it down and maintain mental function.

¹ Source: NHS Choices
www.nhs.uk/conditions/dementia-guide/pages/about-dementia.aspx
Preventing well

• There is evidence that some factors – particularly around cardiovascular risk – can impact on the risk of developing dementia. To have their greatest impact on reducing dementia risk these factors should be controlled throughout middle age (45-64).

Diagnosing well

• Diagnosis information is collected from GP practices to give a national picture of the prevalence of diagnosed dementia:
  – Diagnosed prevalence increased from 643 per 100,000 in April 2014 to 755 per 100,000 in December 2015, which is 423,000 diagnoses out of 56.0m registered patients.

• Recording inconsistencies are found in nearly half of inpatient admissions for people previously recorded as having dementia.
Supporting well

- Carers of people with dementia assess their own quality of life as 7.7 out of 12 overall. This is lowest in London at 7.3 and highest in the North East at 8.4.

- 39 per cent of carers spent 100 or more hours each week looking after or caring for a person with dementia, with 52 per cent spending 50 hours or more per week.

- Over half (51 per cent) of carers had been in their caring role for more than five years.
Key facts continued

Living well

- Prescriptions of the four National Institute for Health and Care Excellence (NICE) appraised Alzheimer's disease (the commonest cause of dementia) medicines increased from 502,000 items in 2004 to 3.0 million items in 2014.

- At the end of September 2015, there were 109,000 assignments to one of the three mental health care clusters covering cognitive impairment or dementia at:
  - moderate need
  - high need
  - or high physical need or engagement

- Looking at all records from April 2012 to March 2015;
  - The median time for progression between ‘moderate need’ and ‘high need’ is 3 years and 2 months.
  - The median time for progression between ‘high need’ and ‘high physical need or engagement’ is 2 years and 9 months.
Key facts continued

Dementia and mortality

• We analysed the mental health data linked to ONS mortality data to provide information on progression between dementia associated care clusters and death.

• The results of the survival analysis provide a median survival time of 3 years 6 months, from when patients are first assessed as having ‘cognitive impairment or dementia at moderate need’.
  – Median survival from first assessment with ‘cognitive impairment or dementia at high need’ is 2 year 3 months.
  – Median survival from first assessment with ‘cognitive impairment or dementia at high physical need or engagement’ is 1 year and 8 months.
Background – an ageing population

The risk of developing dementia increases as people age. The increase in the older population over recent decades is projected to continue. As the older population increases we would expect to see a similar increase in the number of dementia cases unless the incidence of new dementia cases decreases.

Growth is forecast in all older age groups. By 2051, as many as one in four people (25 per cent) will be aged 65 or over and one in 15 people (7 per cent) aged 85 or over.

In 2011, there were 1.2 million people aged 85 or over.

It is predicted that this will increase to 4.4 million aged 85 or over by 2051.


f = principle projection
What factors can affect the risk of developing dementia?
Smoking in middle age

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

Prevalence of current cigarette smokers in England by age-group 2004 and 2014

Percentage point change in prevalence of current cigarette smokers in England by age-group between 2004 and 2014

Sources: Health Survey for England, 2014: Trend tables
www.hscic.gov.uk/pubs/hse2014trend
Alcohol consumption in 2014 was highest for those aged 55–74. The Chief Medical Officers’ proposed new guidelines\(^1\) for both men and women is that you are safest not to drink regularly more than 14 units per week, to keep health risks from drinking alcohol to a low level.

Proportion of adults drinking more than 14 units per week in 2014, by age group

- **27 per cent** of 45 to 54 year olds drank more than 14 units of alcohol per week
- **29 per cent** of 55 to 64 year olds drank more than 14 units of alcohol per week


Source: Health Survey for England, 2014
Obesity in middle age

The proportion of the population who are overweight or obese\(^1\) increases with age. Within the 45-64 age group it was 12 percentage points higher for men than women.

### Overweight or obese by age group, 2014

<table>
<thead>
<tr>
<th>Age Group</th>
<th>Percentage</th>
</tr>
</thead>
<tbody>
<tr>
<td>16-24</td>
<td>32%</td>
</tr>
<tr>
<td>25-34</td>
<td>51%</td>
</tr>
<tr>
<td>35-44</td>
<td>64%</td>
</tr>
<tr>
<td>45-54</td>
<td>69%</td>
</tr>
<tr>
<td>55-64</td>
<td>74%</td>
</tr>
<tr>
<td>65-74</td>
<td>74%</td>
</tr>
<tr>
<td>75+</td>
<td>74%</td>
</tr>
<tr>
<td>All adults 16+ (62%)</td>
<td></td>
</tr>
</tbody>
</table>

### Rates of those overweight or obese. Aged 45-64 by gender, 2014

- **Men**
  - Obese: 44%
  - Overweight: 33%

- **Women**
  - Obese: 32%
  - Overweight: 33%

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\(^1\)Underweight = BMI less than 18.5kg/m\(^2\).  
Overweight = BMI 25 to less than 30kg/m\(^2\).  
Normal = BMI 18.5 to less than 25kg/m\(^2\).  
Obese = BMI 30kg/m\(^2\) or more.

Sources: Health Survey for England, 2014: Trend tables  
www.hscic.gov.uk/pubs/hse2014trend
Physical inactivity in middle age

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

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

Levels of activity by age group, 2012

<table>
<thead>
<tr>
<th>Age Group</th>
<th>Meets recommendations</th>
<th>Some activity</th>
<th>Low activity</th>
</tr>
</thead>
<tbody>
<tr>
<td>75+</td>
<td>20%</td>
<td>9%</td>
<td>71%</td>
</tr>
<tr>
<td>65-74</td>
<td>47%</td>
<td>14%</td>
<td>39%</td>
</tr>
<tr>
<td>55-64</td>
<td>55%</td>
<td>13%</td>
<td>32%</td>
</tr>
<tr>
<td>45-54</td>
<td>66%</td>
<td>11%</td>
<td>23%</td>
</tr>
<tr>
<td>35-44</td>
<td>69%</td>
<td>12%</td>
<td>20%</td>
</tr>
<tr>
<td>25-34</td>
<td>69%</td>
<td>11%</td>
<td>20%</td>
</tr>
<tr>
<td>16-24</td>
<td>70%</td>
<td>10%</td>
<td>19%</td>
</tr>
</tbody>
</table>

Sources: Health Survey for England, 2014: Trend tables
www.hscic.gov.uk/pubs/hse2014trend
Poor diet in middle age

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

28% in 2003
27% in 2013

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

Sources: Health Survey for England, 2014: Trend tables
www.hscic.gov.uk/pubs/hse2014trend
High blood pressure

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

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\(^1\) Hypertensive uncontrolled: Systolic blood pressure (SBP) at or greater than 140mmHg and Diastolic (DBP) at or greater than 90mmHg, currently taking medication for blood pressure.
Hypertensive untreated: SBP at or greater than 140mmHg and DBP at or greater than 90mmHg, not currently taking medication for blood pressure.
Hypertensive controlled: SBP below 140mmHg and DBP below 90mmHg, currently taking medication for blood pressure.
Normotensive untreated: SBP below 140mmHg and DBP below 90mmHg, not currently taking medication for blood pressure.

\(^2\) In 2014, 27 per cent of adults aged 45-54 and 45 per cent of adults aged 55-64 had high blood pressure.
Sources: Health Survey for England, 2014: Trend tables
www.hscic.gov.uk/pubs/hse2014trend
Between 2003 and 2014, the percentage of adults aged 45-54 with diabetes (seven per cent in 2014) has closely aligned with the rates for all adults (six per cent in 2014). For the 55-64 age group the prevalence of diabetes has remained consistently higher than for all adults and was ten per cent in 2014.

Sources: Health Survey for England, 2014: Trend tables
www.hscic.gov.uk/pubs/hse2014trend
Diabetes prevalence has increased since 2003:

- In men by five percentage points in those aged 45-54 and five percentage points in those aged 55-64.
- In women by two percentage points in those aged 45-54 and three percentage points in those aged 55-64.

### Diabetes prevalence (%) by gender and age-group, 2014

<table>
<thead>
<tr>
<th></th>
<th>Women</th>
<th>All adults</th>
<th>Men</th>
</tr>
</thead>
<tbody>
<tr>
<td>45-54</td>
<td>5</td>
<td>7</td>
<td>9</td>
</tr>
<tr>
<td>55-64</td>
<td>7</td>
<td>10</td>
<td>13</td>
</tr>
</tbody>
</table>

What can improve the diagnosis rate of dementia?
Increasing the diagnosis rate

Recorded dementia prevalence increased from 643 per 100,000 GP registered patients in April 2014 to 755 per 100,000 in December 2015, which is 423,000 diagnoses out of 56.0m GP registered patients.

Since 2014-15 the Quality and Outcomes Framework (QOF) has continued to report on the National Dementia Strategy and Prime Minister's dementia challenge aim to increase the dementia diagnosis rate.

Sources: Quality Outcomes Framework (QOF), Recorded Dementia Diagnoses, April 2014 - March 2015  www.hscic.gov.uk/pubs/qofdemaprilmar15
Quality Outcomes Framework (QOF), Recorded Dementia Diagnoses, December 2015 – www.hscic.gov.uk/pubs/qofdemdec15
Increasing the diagnosis rate

New dementia quality and outcomes framework (QOF): 97 per cent of patients with a recorded diagnosis of dementia were accounted for by those aged 65 or over in December 2015. For those aged 65 and over diagnosed dementia prevalence was 4,245 per 100,000.

Recorded dementia prevalence, per cent of registered GP patients, England, by age group and gender, December 2015

Sources: Quality Outcomes Framework (QOF), Recorded Dementia Diagnoses, April 2014 - March 2015 www.hscic.gov.uk/pubs/qofdemaprilmar15
Quality Outcomes Framework (QOF), Recorded Dementia Diagnoses, December 2015 – www.hscic.gov.uk/pubs/qofdemdec15
Increasing the diagnosis rate

All commissioning regions saw recorded prevalence increases. These increases were between 104 and 121 diagnosis per 100,000 registered patients from April 2014 to December 2015.

The prevalence in those aged 65 or older varies between Commissioning Regions, from 4,068 per 100,000 in Midlands and East of England to 4,469 per 100,000 in the North of England.

Recorded dementia prevalence per 100,000 GP registered patients, all ages, April 2014 to December 2015, by Commissioning Region

Sources: Quality Outcomes Framework (QOF), Recorded Dementia Diagnoses, April 2014 - March 2015 www.hscic.gov.uk/pubs/qofdemapr14mar15
Quality Outcomes Framework (QOF), Recorded Dementia Diagnoses, December 2015 – www.hscic.gov.uk/pubs/qofdemdec15
Diagnosis in hospitals

Recording inconsistencies are found in nearly half of inpatient admissions for people previously recorded as having dementia.

Analysis on five years of longitudinally linked inpatient hospital episode statistics tells us that:

- 317,000 individuals had at least one hospital episode with a recorded diagnosis of dementia\(^1\), during the period April 2010 to March 2015
  - This group of people had 263,000 hospital admissions in 2014/15
  - However, only 51% of these 263,000 admissions in 2014/15 had a recorded diagnosis of dementia. This means that 49% of these admissions did not have a recorded diagnosis, despite previously being recorded in hospital with a diagnosis of dementia.
  - This omission of a recorded diagnosis of dementia goes against clinical coding advice which states that a dementia diagnosis should always be recorded where the patient has dementia as it is always considered to be clinically relevant\(^2\).

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\(^1\) Primary or secondary diagnosis of ICD-10 F00 Dementia in Alzheimer disease, F01 Vascular dementia F02 Dementia in other diseases classified elsewhere

\(^2\) [http://systems.hscic.gov.uk/data/clinicalcoding/codingstandards/publications/codingclinic/dec15ccv5.2.pdf](http://systems.hscic.gov.uk/data/clinicalcoding/codingstandards/publications/codingclinic/dec15ccv5.2.pdf)
National Clinical Coding Standard DGCS.3: Co-morbidities and contains the list of medical conditions and other factors influencing health that are always considered to be clinically relevant
Who cares for people with dementia?
Carers of people with dementia were likely to have no worries about their personal safety\(^1\) (83 per cent) and to feel they are looking after themselves well in terms of sleep and nutrition\(^2\) (55 per cent), in 2014/15. Over a third of carers felt they had encouragement and support\(^3\) (39 per cent). Similar levels felt they had as much social contact as they wanted with people they like\(^4\) (35 per cent).

### Carers’ agreement with survey statements, 2014/15

<table>
<thead>
<tr>
<th>Question</th>
<th>No unmet needs</th>
<th>Some unmet needs</th>
<th>Needs unmet</th>
</tr>
</thead>
<tbody>
<tr>
<td>Q10: Having no worries about their personal safety</td>
<td>83%</td>
<td>28%</td>
<td>15%</td>
</tr>
<tr>
<td>Q9: Getting enough sleep and eating well</td>
<td>55%</td>
<td>47%</td>
<td>17%</td>
</tr>
<tr>
<td>Q12: Having encouragement and support</td>
<td>39%</td>
<td>50%</td>
<td>14%</td>
</tr>
<tr>
<td>Q11: Having the amount and type of social contact they want</td>
<td>35%</td>
<td>61%</td>
<td>14%</td>
</tr>
<tr>
<td>Q8: Having sufficient control over their daily life</td>
<td>23%</td>
<td>61%</td>
<td>15%</td>
</tr>
<tr>
<td>Q7: Spending time as they want and enjoy</td>
<td>17%</td>
<td>65%</td>
<td>17%</td>
</tr>
</tbody>
</table>

\(^1\) Question 10  \(^2\) Question 9  \(^3\) Question 12  \(^4\) Question 11


www.hscic.gov.uk/pubs/psscarersurvey1415
• 1 in 4 carers had a long-standing illness\(^1\) (23 per cent).
• 1 in 5 had a physical impairment or disability\(^1\) (21 per cent).
• Most carers were retired\(^2\) (65 per cent).
• 15 per cent were not in paid employment because of their caring responsibilities 4 per cent were in employment but did not feel supported by their employer\(^3\).

1 Question 21  
2 Question 16  
3 Question 17  
www.hscic.gov.uk/pubs/psscarersurvey1415
2 out of 3 carers (64 per cent) reported that the person with dementia who they care for usually lived with them in 2014/15.

Carers of people with dementia assess their own quality of life as 7.7 out of 12 overall. This is lowest in London at 7.3 and highest in the North East at 8.4.

Carer reported quality of life scores of the carer, where the cared-for person had dementia, England and regions, 2014/15

www.hscic.gov.uk/pubs/psscarersurvey1415
Those cared for in 2014/15 mostly made use of equipment or adaptations to their home\(^1\) (62 per cent).

<table>
<thead>
<tr>
<th>Support or services listed</th>
<th>Used (%)</th>
</tr>
</thead>
<tbody>
<tr>
<td>Equipment or adaptation to their home (such as a wheelchair or handrails)</td>
<td>62%</td>
</tr>
<tr>
<td>Home care/home help</td>
<td>48%</td>
</tr>
<tr>
<td>Lifeline Alarm</td>
<td>42%</td>
</tr>
<tr>
<td>Day centre or day activities</td>
<td>37%</td>
</tr>
<tr>
<td>Support or services to allow you to have a rest from caring for between 1 and 24 hours (e.g. sitting service)</td>
<td>32%</td>
</tr>
<tr>
<td>Support or services allowing you to take a break from caring for more than 24 hours</td>
<td>25%</td>
</tr>
<tr>
<td>Support or services allowing you to take a break from caring at short notice or in an emergency</td>
<td>20%</td>
</tr>
<tr>
<td>They are permanently resident in a care home</td>
<td>19%</td>
</tr>
<tr>
<td>Personal assistant</td>
<td>11%</td>
</tr>
<tr>
<td>Meals Services</td>
<td>8%</td>
</tr>
<tr>
<td>Lunch club</td>
<td>6%</td>
</tr>
</tbody>
</table>

\(^1\) Question 5i

During 2014/15 carers were most likely (90 per cent or more) to have provided practical help including dealing with care services or financial matters or have kept an eye on the cared-for person, and many provided emotional support (85 per cent) and personal care (70 per cent).¹

<table>
<thead>
<tr>
<th>What kinds of things did you usually do for the person you care for?</th>
<th>Percentage</th>
</tr>
</thead>
<tbody>
<tr>
<td>Other practical help</td>
<td>93%</td>
</tr>
<tr>
<td>Keeping an eye on him/her to see he/she is all right</td>
<td>93%</td>
</tr>
<tr>
<td>Helping with paperwork or financial matters</td>
<td>92%</td>
</tr>
<tr>
<td>Helping with dealing with care services and benefits</td>
<td>91%</td>
</tr>
<tr>
<td>Keeping him/her company</td>
<td>88%</td>
</tr>
<tr>
<td>Giving emotional support</td>
<td>85%</td>
</tr>
<tr>
<td>Giving medicines</td>
<td>83%</td>
</tr>
<tr>
<td>Taking him/her out</td>
<td>76%</td>
</tr>
<tr>
<td>Personal care</td>
<td>70%</td>
</tr>
<tr>
<td>Physical help</td>
<td>60%</td>
</tr>
<tr>
<td>Other help</td>
<td>20%</td>
</tr>
</tbody>
</table>

¹ Question 20
www.hscic.gov.uk/pubs/psscarersurvey1415
Carers most frequently spent 100 or more hours each week looking after or caring for a person with dementia\(^1\) (39 per cent), and over half of all carers spent 50 hours or more per week (52 per cent).

<table>
<thead>
<tr>
<th>Time spent by carers each week looking after or helping the person they care for 2014/15</th>
<th>%</th>
</tr>
</thead>
<tbody>
<tr>
<td>Varies - 20 hours or more per week</td>
<td>5%</td>
</tr>
<tr>
<td>Varies - Under 20 hours per week</td>
<td>3%</td>
</tr>
<tr>
<td>100 or more hours per week</td>
<td>39%</td>
</tr>
<tr>
<td>75-99 hours per week</td>
<td>7%</td>
</tr>
<tr>
<td>50-74 hours per week</td>
<td>6%</td>
</tr>
<tr>
<td>35-49 hours per week</td>
<td>6%</td>
</tr>
<tr>
<td>20-34 hours per week</td>
<td>8%</td>
</tr>
<tr>
<td>10-19 hours per week</td>
<td>9%</td>
</tr>
<tr>
<td>0-9 hours per week</td>
<td>7%</td>
</tr>
</tbody>
</table>

\(^1\) Question 19
www.hscic.gov.uk/pubs/psscarersurvey1415
Over half (51 per cent) of carers of people with dementia had been in their caring role for more than five years.¹

Length of time carers had been looking after or helping the person they care for, in years 2014/15

- 20 years or more: 6%
- 15 Years to less than 20 years: 4%
- 10 Years to less than 15 years: 11%
- 5 Years to less than 10 years: 30%
- 3 Years to less than 5 years: 26%
- 1 Year to less than 3 years: 21%
- 6 Months to less than a year: 3%
- Less than 6 months: 1%

¹ Question 18
www.hscic.gov.uk/pubs/psscarersurvey1415
Dementia as the illness progresses
Prescribing in primary care

Prescriptions of the four National Institute for Health and Care Excellence (NICE) appraised Alzheimer's disease (the commonest cause of dementia) medicines increased from 502,000 items in 2004 to 3.0 million items in 2014.

NICE Technology Appraisal Guidance, 2011  www.nice.org.uk/guidance/ta217
Prescribing in primary care

- The net ingredient cost (NIC) rose from 2004 to 2011 peaking at £110.8m. Costs then declined driven by a decrease in the NIC of Donepezil, which fell from £72.3m in 2011 to £3.7m in 2014 after the patent expired and cheaper generic formulations became available.
- There has been a steady increase in the use of these medicines over time. Treatment is initiated by memory specialists and care can be transferred to GPs.

NICE Technology Appraisal Guidance, 2011 www.nice.org.uk/guidance/ta217
Donepezil remained the most commonly prescribed medicine in primary care in 2014, and had the lowest cost per item of the four medicines licensed for management of Alzheimer’s disease.

NICE (National Institute for Health and Care Excellence) guidance recommends Donepezil, Galantamine and Rivastigmine as options for managing mild to moderate Alzheimer’s disease.

Memantine is recommended as an option for those with moderate Alzheimer’s disease who cannot tolerate the other medicines, and for managing severe Alzheimer’s disease.

NICE Technology Appraisal Guidance, 2011 www.nice.org.uk/guidance/ta217
For the most recent data at the end of September 2015 there were 576,000 care clusters assigned to people in the mental health and learning disabilities data set.

- Of these, 109,000 (19 per cent) were one of three Mental Health care clusters associated with dementia at moderate need, high need, or high physical need or engagement. Note that these clusters are substantially – but not exclusively – inclusive of dementia diagnoses.

- Of those 109,000 cluster assignments, 83,000 (76 per cent) had had contact with adult secondary mental health and learning disabilities services during the six month review period.

Source: Mental Health and Learning Disabilities Statistics Monthly Report: Final September and Provisional October
www.hscic.gov.uk/pubs/mhldssep15

1 Cognitive impairment or dementia (moderate need); Cognitive impairment or dementia (high need); Cognitive impairment or dementia (high physical need or engagement)
Progression of dementia

There are three mental health care clusters\(^1\) associated with dementia at moderate need, high need, or high physical need or engagement.

For all records of people aged 30 or over with a record from April 2011 to March 2015:

- The median time for progression between ‘moderate need’ and ‘high need’ was 3 years and 2 months
- The median time for progression between ‘high need’ and ‘high physical need or engagement’ was 2 years and 9 months
- Note that these clusters are substantially – but not exclusively – inclusive of dementia diagnoses.

\(^1\) Cognitive impairment or dementia (moderate need); Cognitive impairment or dementia (high need); Cognitive impairment or dementia (high physical need or engagement)


Source: Mental Health and Learning Disabilities Data Set
In 2014/15, women aged 65 and over were more likely than men of this age to have been assigned to any one of the three dementia-related care clusters¹.

People in Care Clusters 19, 20, or 21 as a percentage of all people aged 65 and over, by gender, 2014/15

<table>
<thead>
<tr>
<th>Care cluster 19 - Cognitive impairment or dementia (moderate need)</th>
<th>Care cluster 20 - Cognitive impairment or dementia (high need)</th>
<th>Care cluster 21 - Cognitive impairment or dementia (high physical need or engagement)</th>
</tr>
</thead>
<tbody>
<tr>
<td>Males</td>
<td>0.8%</td>
<td>0.3%</td>
</tr>
<tr>
<td>Females</td>
<td>1.2%</td>
<td>0.4%</td>
</tr>
<tr>
<td>All</td>
<td>1.0%</td>
<td>0.4%</td>
</tr>
</tbody>
</table>

¹ Cognitive impairment or dementia (moderate need); Cognitive impairment or dementia (high need); Cognitive impairment or dementia (high physical need or engagement)

Source: Mental Health and Learning Disabilities Data Set

Those in the “Other ethnic group” category had the highest likelihood of being in a dementia-related care cluster in 2014/15.

Prevalence of people in dementia-related care clusters by ethnic origin grouping, 2014/15:

- Other ethnic group: 3.9%
- Black/African/Caribbean/Black British: 1.7%
- White: 1.6%
- Mixed/multiple ethnic group: 1.3%
- Asian/Asian British: 1.2%

Source: Mental Health and Learning Disabilities Data Set

1 Cognitive impairment or dementia (moderate need); Cognitive impairment or dementia (high need); Cognitive impairment or dementia (high physical need or engagement)

The average score across all assessed sites was 75 per cent, with mental health and learning disabilities sites receiving the highest average scores in the dementia assessment, undertaken for the first time in 2015.

Assessments looked at how well healthcare providers’ premises are equipped to meet the needs of caring for patients with dementia (looking at flooring, decor and signage, but also other features including availability of handrails and appropriate seating and to a lesser extent, food) and scored providers on a scale of 0 to 100 per cent achievement.

1,333 site assessments were undertaken in 2015.
Dementia and mortality

How does dementia affect mortality?
Dementia and mortality - method

We analysed the mental health data linked to ONS mortality data to provide information on progression between dementia associated care clusters and death:

• Survival analysis\(^1\) was performed on patients observed in the Mental Health Minimum Data Set or the Mental Health and Learning Disabilities Data Set (MHMDS/MHLDDDS) from April 2011 until March 2015.
• Progression between the three dementia associated care clusters and eventual death was analysed over this 4 year period.
• Deaths from any cause were counted not just those recorded as deaths due to dementia.

Survival was defined as the time from the initial assessment to the date of death, or to the end of the study period for those who were still alive.

• ‘Time of initial diagnosis’ is recorded as the date of first entry to a care cluster. A patient needs a record in the previous cluster to be considered as having a ‘first’ entry in this analysis.
• Survival times are given for each care cluster and are irrespective of progression between the clusters. Due to the progressive nature of dementia we would therefore expect survival times for care cluster 19 to be greater than survival times for clusters 20 and 21.
• The survival time of individuals who are still alive at the end of the study is interpreted as being at least as long as the period from entry to study end.
• Everyone with an identifiable first entry date to a cluster has been included in the analysis.

\(^1\) Kaplan-Meier survival estimate method
Dementia and mortality - data

Survival analysis was performed on patients observed in the MHMDS from April 2012 until March 2015, recorded as having a date of first entry to a care cluster covering ‘cognitive impairment or dementia at moderate need, high need, or high physical need or engagement’.

<table>
<thead>
<tr>
<th>Care cluster</th>
<th>Patients recorded having a date of first entry to care cluster during the period</th>
<th>Patients who died during period</th>
<th>Patients who were still alive at the end March 2015</th>
</tr>
</thead>
<tbody>
<tr>
<td>Moderate need</td>
<td>48,671</td>
<td>10,676 22%</td>
<td>37,995 78%</td>
</tr>
<tr>
<td>High need</td>
<td>27,556</td>
<td>9,926 36%</td>
<td>17,630 64%</td>
</tr>
<tr>
<td>High physical need or engagement</td>
<td>8,370</td>
<td>3,727 45%</td>
<td>4,643 55%</td>
</tr>
</tbody>
</table>
The results of the survival analysis provide a median survival time\(^1\) of 3 years 6 months, from when patients are first assessed as having ‘cognitive impairment or dementia at moderate need’.

- Median survival from first assessment with ‘cognitive impairment or dementia at high need’ is 2 year 3 months.
- Median survival from first assessment with ‘cognitive impairment or dementia at high physical need or engagement’ is 1 year and 8 months.
- Note that these clusters are substantially – but not exclusively – inclusive of dementia diagnoses.

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\(^1\) Median survival time is the time at which 50 per cent of patients are still alive.
This publication aims to inform you of some of the key health and care issues facing people with dementia. It has not attempted to answer all of the questions there may be surrounding dementia today.

The findings presented are not exhaustive and simply give an example of the kind of information that can be made available about dementia.

We hope that it raises a number of questions and inspires people to look further and ask what else it is we need to know to be able to adequately provide health and care systems that meet needs of people with dementia today and in the future.

**Rounding**

- Counts over 1 million have been rounded to the nearest 100,000
- Counts over 10,000 are rounded to the nearest 1,000
- Counts over 1,000 are rounded to the nearest 100
- Percentages are rounded to the nearest per cent (apart from when dealing with some percentages lower than 10 per cent)
Further information

Policy context

- On 21 February 2015 The Prime Minister’s Challenge[^1] on Dementia 2020 was published, building on the Prime Minister’s Challenge on Dementia 2012-2015.

Dementia profiles

The Dementia Intelligence Network launched a dementia profile and data catalogue[^2] on 12 January 2016

- The dementia profile gives commissioners, local decision makers and health professionals access to local data and intelligence across the whole pathway of dementia care; from prevalence and diagnosis through to end of life. It will enable local teams to transparently compare themselves against other areas in England, or those with similar demographics.

- Accompanying the dementia profile is a data catalogue, which lists and grades all of the dementia data that the DIN is currently aware of or has had requests for. The data catalogue is the first step in ensuring all gaps in dementia data are filled, and aims to stimulate conversation across organisations and promote joint working to make more data available for potential inclusion within the dementia profile.


Data sources

Office for National Statistics (ONS)

The Office for National Statistics (ONS) is the UK’s national statistical institute and the largest producer of official statistics in the UK. It is the only government department with the production of statistics as its main role. ONS is independent of ministers and instead reports through the UK Statistics Authority to Parliament and the devolved administrations of Scotland, Wales and Northern Ireland.

ONS is the executive office of the UK Statistics Authority and although they are separate, they are still closely related. The Statistics and Registration Service Act 2007 sets the Statistics Authority the objective of promoting and safeguarding the production and publication of official statistics which serve the public good. This includes, but is not exclusive to, the needs of government.

As the executive office of the Statistics Authority its main responsibilities are:

• The collection, compilation, analysis and dissemination of a range of key economic, social and demographic statistics about the UK
• The provision of statistical leadership and methodological advice for the benefit of UK official statistics
• Representation of the UK internationally as the national statistical institute.

These responsibilities span more than 650 different statistical releases a year which rely on a broad range of methods and systems. All outputs are produced in line with the ‘Code of Practice for Official Statistics’ and relevant quality standards. This is carried out to align with the Statistics Authority’s responsibility to promote and safeguard official statistics.

Data from the ONS used in this publication includes:

• ONS mortality data
• ONS Population Projections
• ONS Census 1951 – 2011
Health Survey for England, 2014

The Health Survey for England has provided an annual snapshot of the health of the nation and monitored changes over time for over twenty years. The surveys cover the adult and child population living in private households in England. The sample excludes people living in institutions such as care homes.

The surveys include measurements such as height and weight to measure obesity and blood pressure and many questions about health topics, e.g. smoking, alcohol, diabetes and long-standing illness. The sample in the 2014 survey was 8,077 adults (aged 16 and over) and 2,003 children (aged 0-15). For many topics data are available for 10 or more years.

Quality Outcomes Framework (QOF), Recorded Dementia Diagnoses

The Quality and Outcomes Framework (QOF) is the annual reward and incentive programme detailing GP practice achievement results. It rewards practices for the provision of quality care and helps standardise improvement in the delivery of primary medical services. It is a voluntary process for all surgeries in England and was introduced as part of the GP contract in 2004.

The Department of Health (DH), on behalf of the Secretary of State and NHS England (NHSE), directed the HSCIC to establish a data collection in order to received specific dementia diagnosis data to support the National Dementia Strategy and the Prime Minister’s Dementia Challenge, within which there is an ambition to improve the national diagnosis rate of dementia.

For each practice collected in the extract, the HSCIC receives a count of patients who have a diagnosis of dementia on their GP patient record. The HSCIC also receives counts of patients registered at each practice. This data is combined to produce dementia prevalence rates.

This bulletin presents a summary of prescriptions dispensed in the community in England, by community pharmacists, appliance contractors, dispensing doctors and prescriptions for items personally administered in general practices.

The specific source for these statistics is the Prescription Cost Analysis (PCA) data. The Health and Social Care Information Centre (HSCIC) publishes the Prescription Cost Analysis National Statistic, based on PCA figures for the most recent calendar year, annually, in April.

The bulletin highlights changes between 2013 and 2014 and presents the main trends between 2004 and 2014 and within therapeutic areas, based on British National Formulary (BNF) classifications.

Mental Health and Learning Disabilities Statistics Monthly Report: Final September and Provisional October

This statistical release makes available the most recent Mental Health and Learning Disabilities Dataset (MHLDDS) final monthly data. This publication presents a wide range of information about care delivered to users of NHS funded secondary mental health and learning disability services in England.

The MHLDDS covers not only services provided in hospitals, but also in outpatient clinics and in the community, where the majority of people in contact with these services are treated. It brings together key information from the mental health, learning disabilities or autism spectrum disorder care pathway that has been captured on clinical systems as part of patient care. During processing, this information is compiled into a single patient record.

Submission of MHLDDS data is mandatory for NHS funded care, including independent sector providers. Data for clients who are wholly funded by any means that is not NHS, can be submitted on an optional basis.
Patient-Led Assessments of the Care Environment (PLACE), England 2015

This publication reports the scores from the Patient-Led Assessments of the Care Environment (PLACE) programme. These self-assessments are undertaken by teams of NHS and private/independent health care providers, and include at least 50 per cent members of the public (known as patient assessors). They focus on the environment in which care is provided, as well as supporting non-clinical services such as cleanliness, food, hydration, and the extent to which the provision of care with privacy and dignity is supported. The self-assessments are carried out voluntarily.

The assessments undertaken in 2015 were the third under this programme.

The number of assessments undertaken was 1,333.

In 2015, for the first time the assessments considered aspects of the environment in relation to the provision of care to those with dementia. This does not represent a comprehensive assessment relating to dementia, rather it focussed on a limited range of aspects with strong environmental or buildings-associated components.

Personal Social Services Survey of Adult Carers in England

The Personal Social Services Survey of Adult Carers in England is a biennial survey that took place for the second time in 2014-15. The survey covers informal, unpaid carers aged 18 or over, caring for a person aged 18 or over, where the carer has been assessed or reviewed, either separately or jointly with the cared-for person, by social services during the 12 months prior to the sample being identified. Carers were sent questionnaires, issued by Councils with Adult Social Services Responsibilities (CASSRs), in the period October to November 2014. CASSRs reported that 286,910 carers were assessed or reviewed in the 12 months prior to the 2014-15 survey. 57,380 out of a sample of 131,105 carers responded to the survey.

The mandatory survey questions and sample criteria were not changed between the 2012-13 and 2014-15 surveys, however a weighting methodology has been introduced for the 2014-15 survey.