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Information Centre

# Patients in England with a record of dementia diagnosis on their clinical record: April 2015

Quality and Outcomes Framework dementia subset

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Following a specific request from Department of Health and NHS England, this publication gives more timely information on dementia prevalence.

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## Background

The Department of Health (DH), on behalf of the Secretary of State and NHS England (NHSE), have directed the HSCIC to establish a data collection in order to receive specific dementia diagnosis data to support the National Dementia Strategy<sup>1</sup> and the Prime Minister's Dementia Challenge<sup>2</sup>, which aims to improve the national diagnosis rate of dementia.

When the HSCIC receives such a direction we issue a Data Provision Notice<sup>3</sup> to the appropriate providers of the required data.

## Executive Summary

- Recorded dementia prevalence at 30<sup>th</sup> April 2015 is 0.760 per cent (1 person in 132).
- When considered alongside monthly data collected in 2014/15, this indicates a progressive increase in recorded prevalence from March 2015 (0.738) to April 2015 (0.760).
- After adjustments to remove spurious, 'non-GP' practices, shared practices and practices which decided not to participate in this extraction, the extract cohort available for collection was 7,658 practices.
- Of the extract cohort, data for 7,292 practices was collected, representing 95.2 per cent coverage of practices and 95.6 per cent of registered patients.

## Measures associated with dementia

There are a number of measures used to assess the number of patients with dementia, and those who have had a formal diagnosis. We define these as follows:

### Recorded prevalence

Dementia register data are a component of the Quality and Outcomes Framework (QOF)<sup>4</sup>. For 2013/14 to present, patients with a diagnosis of dementia are collected for indicator 'DEM001'. This indicator states:

*The contractor establishes and maintains a register of patients diagnosed with dementia*

For each practice collected in this extract, the HSCIC receives a count of patients who have a diagnosis of dementia on the GP patient record, as defined by the QOF business rules<sup>5</sup> (version 31.0). No personal identifiable data (PID) are collected through this mechanism; only an aggregate/total number of patients with a diagnosis at each practice, by five year age band and gender.

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<sup>1</sup> <http://www.alzheimers.org.uk/ndse>

<sup>2</sup> <https://www.gov.uk/government/publications/prime-ministers-challenge-on-dementia-2020>

<sup>3</sup> [https://www.gov.uk/government/uploads/system/uploads/attachment\\_data/file/450355/dpndementia.pdf](https://www.gov.uk/government/uploads/system/uploads/attachment_data/file/450355/dpndementia.pdf)

<sup>4</sup> <http://www.nhsemployers.org/your-workforce/primary-care-contacts/general-medical-services/quality-and-outcomes-framework>

<sup>5</sup> <http://www.hscic.gov.uk/qofesextractspecs>

The HSCIC also receives counts of patients registered at each practice. Again, these are non-PID aggregate/total counts for each practice.

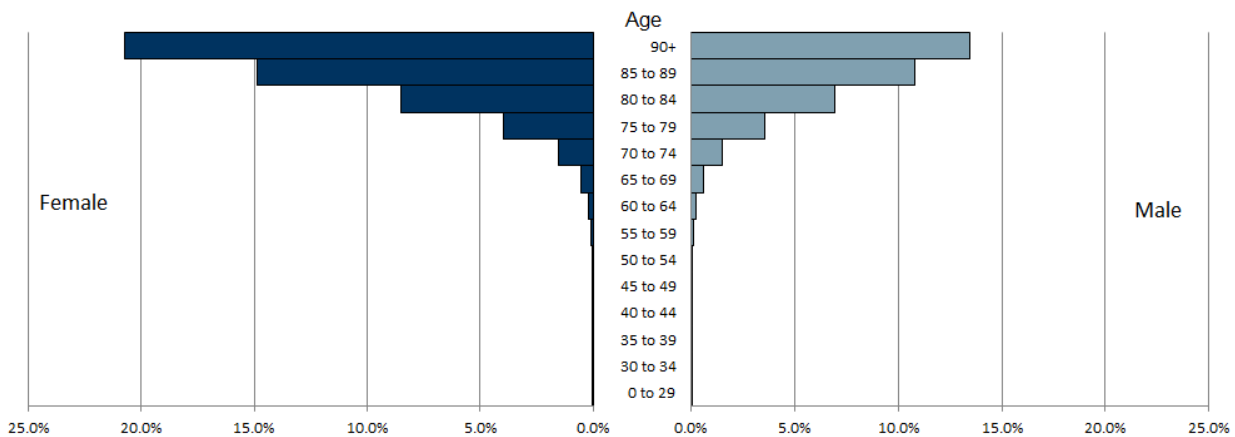
Using these data recorded prevalence for each practice can be calculated as follows:

$$\text{Recorded dementia prevalence} = \left( \frac{\text{Number of patients on dementia register}}{\text{Number of patients registered at practice}} \right) \times 100$$

## Recorded prevalence of dementia

As shown in Figure 1, a gender and age breakdown of the recorded prevalence of dementia reveals only minor inequality between genders up to age 80, above which females experience markedly higher rates of dementia. Table 1 below shows the supporting data for figure 1.

**Figure 1: Observed prevalence of dementia in England by age group and gender**



**Table 1: Observed prevalence of dementia in England by age group and gender**

Age group (years)	Prevalence (%)	
	Male	Female
0 to 29	0.000	0.000
30 to 34	0.001	0.001
35 to 39	0.002	0.002
40 to 44	0.005	0.005
45 to 49	0.016	0.013
50 to 54	0.040	0.041
55 to 59	0.110	0.106
60 to 64	0.253	0.221
65 to 69	0.571	0.530
70 to 74	1.486	1.528
75 to 79	3.550	3.943
80 to 84	6.923	8.497
85 to 89	10.816	14.888
90+	13.443	20.754

**Table 2: Time Series of Recorded Dementia Prevalence, in England as at the 30<sup>th</sup> April 2015**

Year	Total patient list size (thousands)	QOF recorded prevalence		Practice Coverage <sup>1,2</sup>	
		Number (thousands)	Per cent	Number	Per cent
2006/07 <sup>a</sup>	53,681	213	0.396	8,372	-
2007/08 <sup>a</sup>	54,010	220	0.408	8,294	-
2008/09 <sup>a</sup>	54,311	232	0.428	8,229	-
2009/10 <sup>a</sup>	54,837	249	0.455	8,305	-
2010/11 <sup>a</sup>	55,170	267	0.483	8,245	-
2011/12 <sup>a</sup>	55,526	294	0.529	8,123	-
2012/13 <sup>a</sup>	56,012	319	0.569	8,020	-
2013/14 <sup>a</sup>	56,336	344	0.620	7,928	-
2014/15 <sup>a</sup>	56,818	419	0.738	7,779	-
April 2014 <sup>a</sup>	51,629	332	0.643	7,201	92.3
May 2014 <sup>a</sup>	50,792	328	0.646	7,077	90.7
June 2014 <sup>a</sup>	51,914	336	0.647	7,207	92.4
July 2014 <sup>a</sup>	51,931	337	0.649	7,230	92.9
August 2014 <sup>a</sup>	51,811	333	0.644	7,170	92.1
September 2014 <sup>a</sup>	52,221	336	0.644	7,185	93.5
October 2014 <sup>a</sup>	52,849	349	0.660	7,304	95.4
November 2014 <sup>a</sup>	52,292	354	0.677	7,193	94.1
December 2014 <sup>a</sup>	53,220	369	0.694	7,289	95.0
January 2015 <sup>a</sup>	52,830	371	0.703	7,255	94.7
February 2015 <sup>a</sup>	52,681	377	0.716	7,198	94.0
March 2015 <sup>a</sup>	54,794	401	0.731	7,486	97.3
April 2015 <sup>b</sup>	53,996	410	0.760	7,293	95.2
May 2015 <sup>b</sup>	52,339	397	0.758	7,059	92.2
June 2015 <sup>b</sup>	55,221	418	0.757	7,437	97.2
July 2015 <sup>b</sup>	55,325	418	0.756	7,439	97.7
August 2015 <sup>b</sup>	53,730	403	0.749	7,162	95.6
September 2015 <sup>b</sup>	55,324	414	0.748	7,396	97.2
October 2015 <sup>b</sup>	55,725	418	0.750	7,439	97.5

<sup>1</sup>Practice coverage indicates practices for which data were collected as a percentage of those practices in the 'extract cohort'. The 'extract cohort' does not include practices which did not participate in the collection.

<sup>2</sup>Coverage figures are not calculated for published year-end QOF data as these are considered a 'complete' collection of data participating in the QOF (effectively 100 per cent).

<sup>a</sup>Patient list size extracted from practices alongside QOF indicator data.

<sup>b</sup>Patient list size extracted from HSCIC maintained GP Payments system, publicly available at <http://www.hscic.gov.uk/article/2021/Website-Search?q=Numbers+of+Patients+Registered+at+a+GP+Practice&go=Go&area=both>

## What data are included in this release?

This report contains a small amount of summarised data and analysis. Data are also provided at practice level in the accompanying (csv) file. The following data items are included:

### Practice code

The code of the GP practice

### Practice name

The name of the GP practice

### CCG code

This is the parent clinical commissioning group of the practice.

### ONS code

All statistical geographies within England have a 9-digit ONS code. These codes ensure that all geographies are referenced consistently across government to allow data to be aggregated, linked, presented and compared on a common base.

### Dementia register (for each month) for patients aged 0-64 and 65+ years old

This is the number of patients registered at the GP practice, with a diagnosis of dementia (as defined by the QOF dementia register code cluster), as at the end of the specified month, split by age group (0-64/65+ years).

## Which practices are included in the dataset?

The GP Extraction Service (GPES) extracts data for practices that were open at the relevant date point, being the last day of the month for which data were extracted. We call this the 'total estate'. This estate only includes those practices defined as a 'GP Practice' on the organisational reference data we hold (sourced from TRUD<sup>6</sup>). We do not include practices defined as walk-in centres, out of hours clinics, or prison prescribing cost centres. A further adjustment to the total estate from previous extracts is to also exclude 'shared' and 'dormant' practices.

**Shared practices** are those practices which share a clinical system. GPES cannot extract data from these practices, so they are excluded.

**Dormant practices** are those practices where the practice code has yet to be fully closed down, but which are no longer active GP practices. As such there are no data for GPES to extract.

The GPES extract is not instantaneous; it runs over a number of days – known as the "extract window". Depending on the length of this window, GPES may not manage to collect data for all potential practices.

The table below shows the coverage returned for each extract. Coverage is calculated as those practices for which we collected data, as a percentage of those practices from which we attempted to collect (the 'extract cohort' being 'total estate' less practices not opting in).

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<sup>6</sup> Technology Reference data Update Distribution - <https://isd.hscic.gov.uk/trud3/user/guest/group/0/home>



**Table 3: National coverage of GPES dementia extracts**

	Apr-15	
	Practices (number)	Proportion (%)
Active practices in England	7,864	-
Total estate <sup>1</sup>	7,773	98.84
Extract cohort <sup>2</sup>	7,658	97.38
Data collected	7,292	92.73
Collection not possible	91	1.16
Collection not successful	366	4.65
Not opted-in	115	1.46
Other extracted <sup>3</sup>	1	-

<sup>1</sup>Active practices from which it is possible to collect data

<sup>2</sup>Practices in the total estate which have opted-in to data collection

<sup>3</sup>Includes inactive practices from which data was successfully extracted

The cohorts change over time, generally this is because practices will have opened and closed in the intervening period, and additional practices may choose to participate in the collection.

## Why are these data released before the annual QOF publication?

The most recent annual QOF publication was released on 29<sup>th</sup> October 2015. The annual publication contains data covering all QOF indicators for 2014/15, of which dementia is one component. Data for 2015/16 will be published in October 2016. There is a substantial lead time on the annual publication to finalise and compile the data, and to produce the publication itself. Hence, the publication date in October is seven months after the year end. The disease registers (including dementia) produced in this publication are taken to represent the recorded prevalence rate for the reporting year and are used in any analysis of QOF recorded prevalence rates over recent years.

Monthly dementia register data are an extract of a register taken specifically for the monitoring of recorded prevalence and diagnosis rate to allow DH and NHS England to monitor progress toward the 67 per cent diagnosis rate ambition<sup>7</sup>. As a smaller and less complex data set than the full QOF data, the lead time is much shorter, and a timely release of these data is essential to assist with monitoring.

<sup>7</sup> <http://www.england.nhs.uk/wp-content/uploads/2013/12/5yr-strat-plann-guid-wa.pdf>

## What are the plans for releasing data for other months?

This release adds data to those previously published for 2014/15. Data are published at regular monthly intervals during 2015/16 continuing the time-series until all data for 2015/16 are released. Future publications will contain retrospective data until we have published data from the beginning of the financial year. While previous month's data are being released, we will also release the most recent data available in between the retrospective months.

Future publication dates can be viewed on the HSCIC publication planner<sup>8</sup>.

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<sup>8</sup> <http://www.hscic.gov.uk/pubs/calendar>

## ANNEX 1: Quality Outcomes Framework definition of dementia

### Read V2 codes

Read V2 Code	Description
A4110	Sporadic Creutzfeldt-Jakob disease
E00..	Senile and presenile organic psychotic conditions
E000.	Uncomplicated senile dementia
E001.	Presenile dementia
E0010	Uncomplicated presenile dementia
E0011	Presenile dementia with delirium
E0012	Presenile dementia with paranoia
E0013	Presenile dementia with depression
E001z	Presenile dementia NOS
E002.	Senile dementia with depressive or paranoid features
E0020	Senile dementia with paranoia
E0021	Senile dementia with depression
E002z	Senile dementia with depressive or paranoid features NOS
E003.	Senile dementia with delirium
E004.	Arteriosclerotic dementia
E0040	Uncomplicated arteriosclerotic dementia
E0041	Arteriosclerotic dementia with delirium
E0042	Arteriosclerotic dementia with paranoia
E0043	Arteriosclerotic dementia with depression
E004z	Arteriosclerotic dementia NOS
E00y.	Other senile and presenile organic psychoses
E00z.	Senile or presenile psychoses NOS
E012.	Other alcoholic dementia
E0120	Chronic alcoholic brain syndrome
E02y1	Drug-induced dementia
E041.	Dementia in conditions EC
Eu00.	[X]Dementia in Alzheimer's disease
Eu000	[X]Dementia in Alzheimer's disease with early onset
Eu001	[X]Dementia in Alzheimer's disease with late onset
Eu002	[X]Dementia in Alzheimer's dis, atypical or mixed type

Read V2 Code	Description
Eu00z	[X]Dementia in Alzheimer's disease, unspecified
Eu01.	[X]Vascular dementia
Eu010	[X]Vascular dementia of acute onset
Eu011	[X]Multi-infarct dementia
Eu012	[X]Subcortical vascular dementia
Eu013	[X]Mixed cortical and subcortical vascular dementia
Eu01y	[X]Other vascular dementia
Eu01z	[X]Vascular dementia, unspecified
Eu02.	[X]Dementia in other diseases classified elsewhere
Eu020	[X]Dementia in Pick's disease
Eu021	[X]Dementia in Creutzfeldt-Jakob disease
Eu022	[X]Dementia in Huntington's disease
Eu023	[X]Dementia in Parkinson's disease
Eu024	[X]Dementia in human immunodef virus [HIV] disease
Eu025	[X]Lewy body dementia
Eu02y	[X]Dementia in other specified diseases classif elsewhere
Eu02z	[X] Unspecified dementia
Eu041	[X]Delirium superimposed on dementia
F110.	Alzheimer's disease
F1100	Alzheimer's disease with early onset
F1101	Alzheimer's disease with late onset
F111.	Pick's disease
F112.	Senile degeneration of brain
F116.	Lewy body disease

### CTV3 codes

CTV3 Code	Parent CTV3 Code	Description
A410.	X003L	Kuru
A411.	X003L	Creutzfeldt-Jakob disease
E000.	X00R2	Uncomplicated senile dementia
E001.	X002w	Presenile dementia
E0010	E001.	Uncomplicated presenile dementia
E0011	E001.	Presenile dementia with delirium
E0012	E001.	Presenile dementia with paranoia

CTV3 Code	Parent CTV3 Code	Description
E0013	E001.	Presenile dementia with depression
E001z	E001.	Presenile dementia NOS
E002.	X00R2	Senile dementia with depressive or paranoid features
E0020	E002.	Senile dementia with paranoia
E0021	E002.	Senile dementia with depression
E002z	E002.	Senile dementia with depressive or paranoid features NOS
E003.	X00R2	Senile dementia with delirium
E004.	XE1Xs	Arteriosclerotic dementia (including [multi infarct dement])
E0040	XE1Xs	Uncomplicated arteriosclerotic dementia
E0041	XE1Xs	Arteriosclerotic dementia with delirium
E0042	XE1Xs	Arteriosclerotic dementia with paranoia
E0043	XE1Xs	Arteriosclerotic dementia with depression
E004z	XE1Xs	Arteriosclerotic dementia NOS
E00z.	XE1Xr	Senile or presenile psychoses NOS
E041.	X002w	Dementia in conditions EC
Eu00.	F110.	[X]Dementia in Alzheimer's disease
Eu002	F110.	[X]Dementia in Alzheimer's dis, atypical or mixed type
Eu00z	F110.	[X]Dementia in Alzheimer's disease, unspecified
Eu011	XE1Xs	[X]Dementia: [multi-infarct] or [predominantly cortical]
Eu01y	XE1Xs	[X]Other vascular dementia
Eu01z	XE1Xs	[X]Vascular dementia, unspecified
Eu02.	X00Qz	[X]Dementia in other diseases classified elsewhere
Eu020	F111.	[X]Dementia in Pick's disease
Eu021	X003L	[X]Dementia in Creutzfeldt-Jakob disease
Eu022	Eu02.	[X]Dementia in Huntington's disease
Eu023	Eu02.	[X]Dementia in Parkinson's disease
Eu02y	Eu02.	[X]Dementia in other specified diseases classif elsewhere
F110.	Xa1GB	Alzheimer's disease
F111.	X0034	Pick's disease
F11x7	X003L	Cerebral degeneration due to Creutzfeldt-Jakob disease
F21y2	X002w	Binswanger's disease
Fyu30	F110.	[X]Other Alzheimer's disease
X002w	X00Qz	Dementia
X002x	X002w	Dementia in Alzheimer's disease with early onset

<b>CTV3 Code</b>	<b>Parent CTV3 Code</b>	<b>Description</b>
X002y	XaIKB	Familial Alzheimer's disease of early onset
X002z	XaIKB	Non-familial Alzheimer's disease of early onset
X0030	X002w	Dementia in Alzheimer's disease with late onset
X0031	XaIKC	Familial Alzheimer's disease of late onset
X0032	XaIKC	Non-familial Alzheimer's disease of late onset
X0033	F110.	Focal Alzheimer's disease
X0034	X0037	Frontotemporal dementia
X0035	F111.	Pick's disease with Pick bodies
X0036	F111.	Pick's disease with Pick cells and no Pick bodies
X0037	Xa1GB	Frontotemporal degeneration
X0039	X0034	Frontal lobe degeneration with motor neurone disease
X003A	Xa1GB	Lewy body disease
X003G	F110.	Progressive aphasia in Alzheimer's disease
X003G	X003E	Progressive aphasia in Alzheimer's disease
X003H	Xa1GB	Argyrophilic brain disease
X003I	X002w	Post-traumatic dementia
X003J	X003I	Punch drunk syndrome
X003K	X003L	Spongiform encephalopathy
X003L	Xa1GB	Prion protein disease
X003M	X003L	Gerstmann-Straussler-Scheinker syndrome
X003N	X003L	Familial fatal insomnia
X003P	Xa1GB	Acquired immune deficiency syndrome dementia complex
X003R	XE1Xs	Vascular dementia of acute onset
X003T	XE1Xs	Subcortical vascular dementia
X003V	XE1Xs	Mixed cortical and subcortical vascular dementia
X003W	X0037	Semantic dementia
X003X	X002w	Patchy dementia
X003Y	X002w	Epileptic dementia
X00R2	X002w	Senile dementia
Xa0IH	XE1Xs	Multi-infarct dementia
Xa0sC	Xa1GB	Frontal lobe degeneration
Xa0sE	Xa0sC	Dementia of frontal lobe type
Xa1GB	X002w	Cerebral degeneration presenting primarily with dementia
Xa25J	X002w	Alcoholic dementia

<b>CTV3 Code</b>	<b>Parent CTV3 Code</b>	<b>Description</b>
Xa3ez	X002w	Other senile/presenile dementia
XaA1S	A411.	New variant of Creutzfeldt-Jakob disease
XabVp	A411.	Sporadic Creutzfeldt-Jakob disease
XaE74	X003A	Senile dementia of the Lewy body type
XaIKB	F110.	Alzheimer's disease with early onset
XaIKC	F110.	Alzheimer's disease with late onset
XaKyY	Eu02.	[X]Lewy body dementia
XE1aG	X002w	Dementia (& [presenile] or [senile])
XE1Xs	X002w	Vascular dementia
XE1Xt	XE1Xr	Other senile and presenile organic psychoses
XE1Z6	Eu02.	[X]Unspecified dementia

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