



Health & Social Care
Information Centre

Patients in England with a Record of Dementia Diagnosis on Their Clinical Record

Quality Outcomes Framework Dementia Subset

Published October 2015



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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 Strategy¹ and the Prime Minister's Dementia Challenge², within which aims there is an ambition to improve the national diagnosis rate of dementia.

When the HSCIC receives such a direction we issue a Data Provision Notice³ to the appropriate providers of the required data.

Executive Summary

- Recorded dementia prevalence at 31st August 2015 is 0.749 per cent (1 person in 134).
- When considered alongside monthly data collected in 2014/15, this indicates a progressive increase in recorded prevalence from March 2015 (0.731) to August 2015 (0.749).
- 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 7,492 practices.
- Of the extract cohort, data for 7,162 practices was collected, representing 95.6 per cent coverage of practices and 96.6 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 Outcomes Framework (QOF)⁴. 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 rules⁵. No personal identifiable data (PID) are collected through this mechanism; they are simply an

¹ <http://www.alzheimers.org.uk/ndse>

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

³ https://www.gov.uk/government/uploads/system/uploads/attachment_data/file/450355/dpndementia.pdf

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

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

aggregate/total number of patients with a diagnosis at each practice, by five year age band and gender.

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

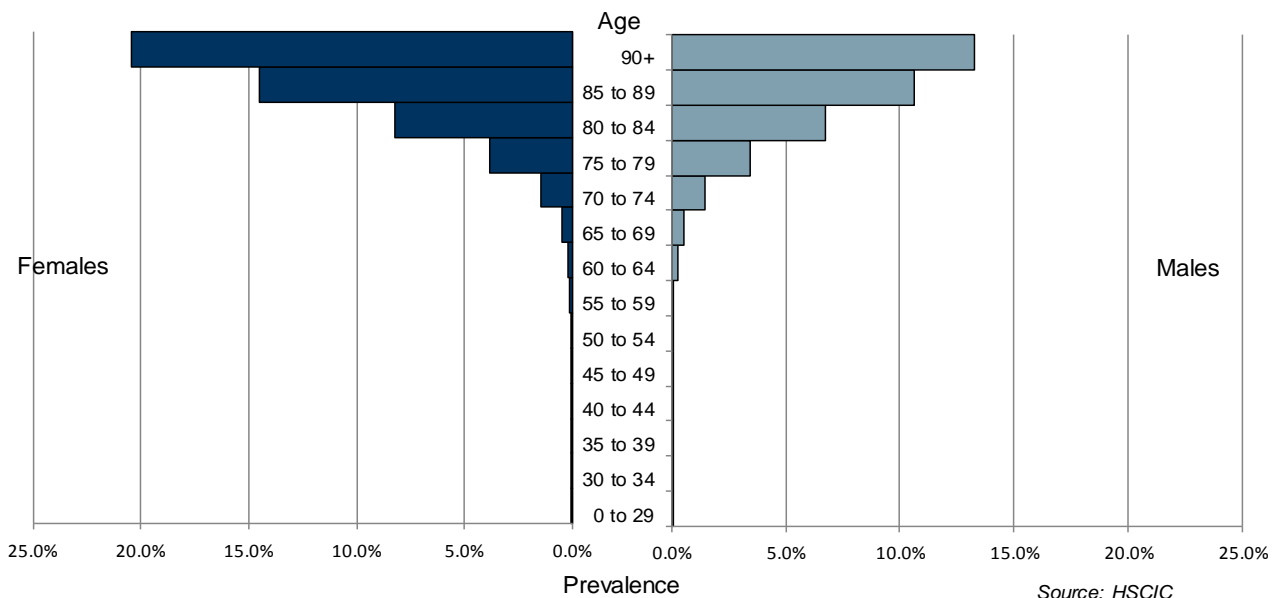


Table 1: Observed prevalence of dementia in England by age group and gender

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	0.015	0.013
50 to 54	0.038	0.041
55 to 59	0.108	0.106
60 to 64	0.249	0.215
65 to 69	0.556	0.519
70 to 74	1.450	1.476
75 to 79	3.457	3.835
80 to 84	6.728	8.211
85 to 89	10.609	14.509
90+	13.269	20.422

Table 2: Time Series of Recorded Dementia Prevalence, in England as at the 31st August 2015

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

¹Practice 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.

²Coverage 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).

^aPatient list size extracted from practices alongside QOF indicator data.

^bPatient 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).

Patient List size (0-64 and 65+ years old)

This is the number of patients registered at the GP practice, as at the end of the specified month, split by age group (0-64/65+ years). This data comes from the Exeter (NHAIS) Extract.

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 TRUD⁶). 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 opting out).

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

Table 3: National coverage of GPES dementia extracts

	Aug-15	
	Practices	Per cent of practices
Total Active Practices in England	7,791	-
Total estate	7,759	-
Not participated in collection ¹	467	6.0
Extract cohort ²	7,492	-
No data collected	330	4.4
Data collected ²	7,162	95.6

¹Includes non-participating, inactive and unextractable practices

²Includes dormant 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 28th October 2014. The annual publication contains data covering all QOF indicators for 2013/14, of which dementia is one component. Data for 2014/15 will be published on 29th October 2015. 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 ambition⁷. 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.

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 were released. August data is being published first as this is the most recent month available at the time data extraction was agreed to take place.

Future publication dates can be viewed on the HSCIC publication planner⁸.

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

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

ANNEX 1: Quality Outcomes Framework definition of dementia

Read codes

Read CODE	TERM ID	NAME
Eu02.	00FAs	Dementia in other diseases classified elsewhere
Eu020	00FAt	Dementia in Pick's disease
Eu021	00FAu	Dementia in Creutzfeldt-Jakob disease
Eu022	00FAv	Dementia in Huntington's disease
Eu023	00FAw	Dementia in Parkinson's disease
Eu024	00FAx	Dementia in human immunodeficiency virus [HIV] disease
Eu025	00FAy	Lewy body dementia
Eu02y	00FAz	Dementia in other specified diseases classified elsewhere
Eu02z	00FB0	Unspecified dementia
E00..	00Eun	Senile and presenile organic psychotic conditions
E000.	00Euo	Uncomplicated senile dementia
E001.	00Eup	Presenile dementia
E0010	00Euq	Uncomplicated presenile dementia
E0011	00Eur	Presenile dementia with delirium
E0012	00Eus	Presenile dementia with paranoia
E0013	00Eut	Presenile dementia with depression
E001z	00Euu	Presenile dementia NOS
E002.	00Euv	Senile dementia with depressive or paranoid features
E0020	00Euw	Senile dementia with paranoia
E0021	00Eux	Senile dementia with depression
E002z	00Euy	Senile dementia with depressive or paranoid features NOS
E003.	00Euz	Senile dementia with delirium
E004.	00Ev0	Arteriosclerotic dementia
E0040	00Ev2	Uncomplicated arteriosclerotic dementia
E0041	00Ev3	Arteriosclerotic dementia with delirium
E0042	00Ev4	Arteriosclerotic dementia with paranoia
E0043	00Ev5	Arteriosclerotic dementia with depression
E004z	00Ev6	Arteriosclerotic dementia NOS

Read CODE	TERM ID	NAME
E00y.	00Ev8	Other senile and presenile organic psychoses
E00z.	00Ev9	Senile or presenile psychoses NOS
Eu01.	00FAj	Vascular dementia
Eu010	00FAI	Vascular dementia of acute onset
Eu011	00FAM	Multi-infarct dementia
Eu012	00FAo	Subcortical vascular dementia
Eu013	00FAp	Mixed cortical and subcortical vascular dementia
Eu01y	00FAq	Other vascular dementia
Eu01z	00FAR	Vascular dementia, unspecified
E012.	00EvK	Other alcoholic dementia
E0120	00EvL	Chronic alcoholic brain syndrome
Eu00.	00FAW	Dementia in Alzheimer's disease
Eu000	00FAX	Dementia in Alzheimer's disease with early onset
Eu001	00FAB	Dementia in Alzheimer's disease with late onset
Eu002	00FAf	Dementia in Alzheimer's dis, atypical or mixed type
Eu00z	00FAh	Dementia in Alzheimer's disease, unspecified
F110.	00FTe	Alzheimer's disease
F1100	00FTf	Alzheimer's disease with early onset
F1101	00FTg	Alzheimer's disease with late onset
F111.	00FTH	Pick's disease
F112.	00FTi	Senile degeneration of brain

CTV3 codes

CTV3 CODE	TERM ID	NAME
X002w	Y00Gv	Dementia
Xa1GB	Ya2nk	Cerebral degeneration presenting primarily with dementia
F110.	Y00Gw	Alzheimer's disease
Xa1KB	YMAhP	Alzheimer's disease with early onset
X002y	Y00H3	Familial Alzheimer's disease of early onset
X002z	Y00H4	Non-familial Alzheimer's disease of early onset
Xa1KC	YMAhQ	Alzheimer's disease with late onset

CTV3 CODE	TERM ID	NAME
X0031	Y00H8	Familial Alzheimer's disease of late onset
X0032	Y00H9	Non-familial Alzheimer's disease of late onset
X0033	Y00HA	Focal Alzheimer's disease
X003G	Y00HV	Progressive aphasia in Alzheimer's disease
Eu00.	YMB0i	Dementia in Alzheimer's disease
Eu002	YMB0l	Dementia in Alzheimer's dis, atypical or mixed type
Eu00z	YMB0m	Dementia in Alzheimer's disease, unspecified
Fyu30	YMADH	Other Alzheimer's disease
Xa0sC	Y00HG	Frontal lobe degeneration
Xa0sE	Y00HH	Dementia of frontal lobe type
X003A	Y00HL	Lewy body disease
XaE74	Y00HN	Senile dementia of the Lewy body type
X0037	Ya1Sy	Frontotemporal degeneration
X0034	Y00HB	Frontotemporal dementia
F111.	Y00HC	Pick's disease
X0035	Y00HD	Pick's disease with Pick bodies
X0036	Y00HE	Pick's disease with Pick cells and no Pick bodies
Eu020	YMB0v	Dementia in Pick's disease
X0039	Y00HK	Frontal lobe degeneration with motor neurone disease
X003E	Y00HT	Progressive aphasia
X003F	Y00HU	Non-Alzheimer's progressive dysphasia
X003G	Y00HV	Progressive aphasia in Alzheimer's disease
X003W	Y00I2	Semantic dementia
X003H	Y00HW	Argyrophilic brain disease
X003L	Y00Hb	Prion protein disease
A411.	Yadym	Creutzfeldt-Jakob disease
XaA1S	YaYo5	New variant of Creutzfeldt-Jakob disease
X003M	Y00Hh	Gerstmann-Straussler-Scheinker syndrome
A410.	Y00Hk	Kuru
X003N	Y00Hi	Familial fatal insomnia
X003K	Y00Ha	Spongiform encephalopathy
Eu021	YMB0w	Dementia in Creutzfeldt-Jakob disease

CTV3 CODE	TERM ID	NAME
F11x7	Yady4	Cerebral degeneration due to Creutzfeldt-Jakob disease
X001T	Y00DV	Limbic encephalitis
X003P	Y00Hq	Acquired immune deficiency syndrome dementia complex
XE1Xs	Y00Hv	Vascular dementia
X003R	Y00Hx	Vascular dementia of acute onset
X003T	Y00Hz	Subcortical vascular dementia
X003V	Y00I1	Mixed cortical and subcortical vascular dementia
Xa0IH	YadT0	Multi-infarct dementia
E0040	Y0170	Uncomplicated arteriosclerotic dementia
E0041	Y016z	Arteriosclerotic dementia with delirium
E0042	Y016w	Arteriosclerotic dementia with paranoia
E0043	Y016x	Arteriosclerotic dementia with depression
E004z	Y016y	Arteriosclerotic dementia NOS
Eu01y	YMB0s	Other vascular dementia
Eu01z	YMB0t	Vascular dementia, unspecified
E004.	YE19s	Arteriosclerotic dementia (including [multi infarct dementia])
Eu011	YE1yt	Dementia: [multi-infarct] or [predominantly cortical]
F21y2	Y00I0	Binswanger's disease
X003Y	Y00I4	Epileptic dementia
X003I	Y00HX	Post-traumatic dementia
X003J	Y00HY	Punch drunk syndrome
Xa25J	Ya3yA	Alcoholic dementia
X00R2	Y016Y	Senile dementia
E000.	Y016e	Uncomplicated senile dementia
E002.	Y016a	Senile dementia with depressive or paranoid features
E0020	Y016b	Senile dementia with paranoia
E0021	Y016c	Senile dementia with depression
E002z	Y016d	Senile dementia with depressive or paranoid features NOS
E003.	Y016Z	Senile dementia with delirium
X002x	Y00H0	Dementia in Alzheimer's disease with early onset
X0030	Y00H5	Dementia in Alzheimer's disease with late onset
E001.	Y016S	Presenile dementia

Patients in England with a Record of Dementia Diagnosis on Their Clinical Record: August 2015

CTV3 CODE	TERM ID	NAME
E0010	Y016T	Uncomplicated presenile dementia
E0011	Y016U	Presenile dementia with delirium
E0012	Y016V	Presenile dementia with paranoia
E0013	Y016W	Presenile dementia with depression
E001z	Y016X	Presenile dementia NOS
E041.	Y016f	Dementia in conditions EC
X003X	Y0013	Patchy dementia
Xa3ez	Ya64O	Other senile/presenile dementia
XE1aG	YE1CY	Dementia (& [presenile] or [senile])
Eu02.	YMB0u	Dementia in other diseases classified elsewhere
Eu022	YMB0x	Dementia in Huntington's disease
Eu023	YMB0y	Dementia in Parkinson's disease
Eu02y	YMB10	Dementia in other specified diseases classif elsewhere
XE1Z6	YMB11	Unspecified dementia
XaKyY	Yao4l	Lewy body dementia
X003E	Y00HT	Progressive aphasia
X003F	Y00HU	Non-Alzheimer's progressive dysphasia
X003G	Y00HV	Progressive aphasia in Alzheimer's disease
Xa1GB	Ya2nk	Cerebral degeneration presenting primarily with dementia
F110.	Y00Gw	Alzheimer's disease
XaIKB	YMAhP	Alzheimer's disease with early onset
X002y	Y00H3	Familial Alzheimer's disease of early onset
X002z	Y00H4	Non-familial Alzheimer's disease of early onset
XaIKC	YMAhQ	Alzheimer's disease with late onset
X0031	Y00H8	Familial Alzheimer's disease of late onset
X0032	Y00H9	Non-familial Alzheimer's disease of late onset
X0033	Y00HA	Focal Alzheimer's disease
X003G	Y00HV	Progressive aphasia in Alzheimer's disease
Eu00.	YMB0i	Dementia in Alzheimer's disease
Eu002	YMB0l	Dementia in Alzheimer's dis, atypical or mixed type
Eu00z	YMB0m	Dementia in Alzheimer's disease, unspecified
Fyu30	YMADH	Other Alzheimer's disease

CTV3 CODE	TERM ID	NAME
Xa0sC	Y00HG	Frontal lobe degeneration
Xa0sE	Y00HH	Dementia of frontal lobe type
X003A	Y00HL	Lewy body disease
XaE74	Y00HN	Senile dementia of the Lewy body type
X0037	Ya1Sy	Frontotemporal degeneration
X0034	Y00HB	Frontotemporal dementia
F111.	Y00HC	Pick's disease
X0035	Y00HD	Pick's disease with Pick bodies
X0036	Y00HE	Pick's disease with Pick cells and no Pick bodies
Eu020	YMB0v	Dementia in Pick's disease
X0039	Y00HK	Frontal lobe degeneration with motor neurone disease
X003E	Y00HT	Progressive aphasia
X003F	Y00HU	Non-Alzheimer's progressive dysphasia
X003G	Y00HV	Progressive aphasia in Alzheimer's disease
X003W	Y00I2	Semantic dementia
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XaA1S	YaYo5	New variant of Creutzfeldt-Jakob disease
X003M	Y00Hh	Gerstmann-Straussler-Scheinker syndrome
A410.	Y00Hk	Kuru
X003N	Y00Hi	Familial fatal insomnia
X003K	Y00Ha	Spongiform encephalopathy
Eu021	YMB0w	Dementia in Creutzfeldt-Jakob disease
F11x7	Yady4	Cerebral degeneration due to Creutzfeldt-Jakob disease
X001T	Y00DV	Limbic encephalitis
X003P	Y00Hq	Acquired immune deficiency syndrome dementia complex

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