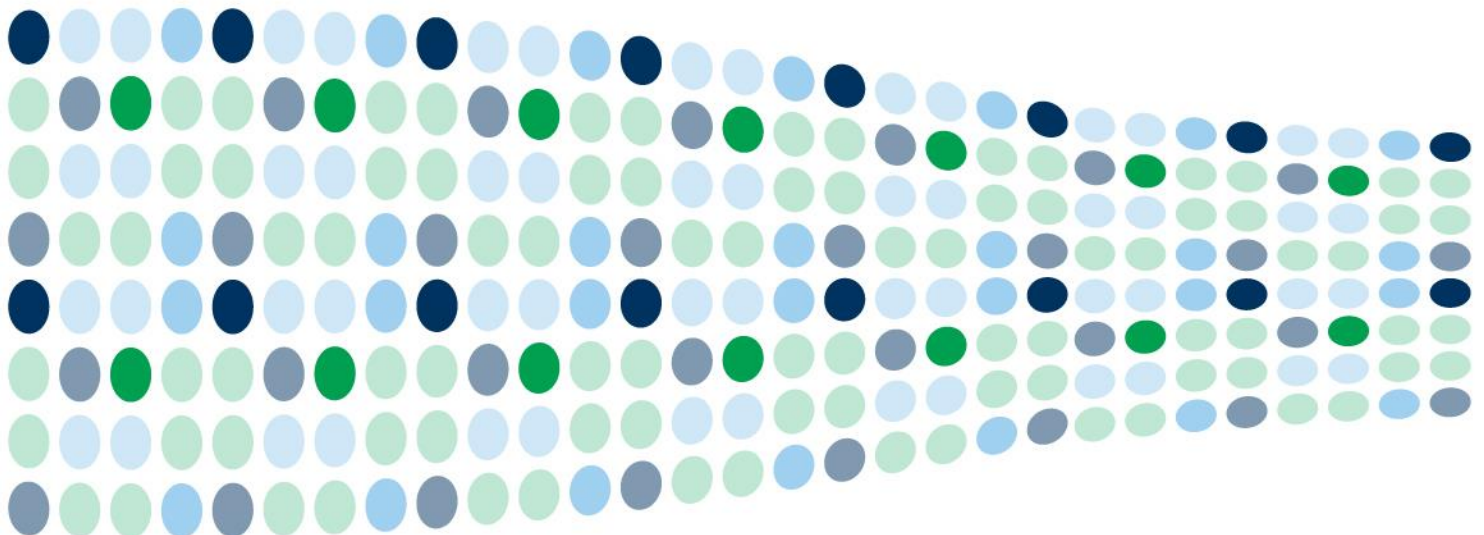




Health & Social Care  
Information Centre

# Quality Outcomes Framework (QOF) Recorded Dementia Diagnoses

**March 2015**



Published 16<sup>th</sup> April 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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<b>Version:</b>	<b>V1.0</b>
<b>Date of publication:</b>	<b>16<sup>th</sup> April 2015</b>

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# 1.0 Background

These data are published in support of the Dementia Strategy and the Dementia Challenge.

The Quality and Outcome Framework (QOF) subset 2014-15 dementia data extraction supports the Prime Minister's Dementia Challenge, within which aims there is an ambition to improve the national diagnosis rate of dementia.

The HSCIC has been asked by the Secretary of State for Health to collect dementia diagnosis data on a monthly basis from general practice clinical systems. These are the same<sup>1a</sup> data that will be collected later in the year as part of the Quality and Outcomes Framework data 2014-15.

Following agreement and support from the Joint GP IT Committee of the British Medical Association and the Royal College of GPs, the HSCIC extracted these data using GPES. GP practices were given the opportunity to opt out of the extract, and some practices exercised this option (<http://www.hscic.gov.uk/article/4863/Quality-and-Outcomes-Framework-subset-2014-15-dementia-data-extraction>).

Other releases in this series include:

Provisional QOF 2013/14 dementia recorded diagnoses

<http://www.hscic.gov.uk/catalogue/PUB14624>

Initial release of dementia recorded diagnoses data for August 2014 on 10<sup>th</sup> September

<http://www.hscic.gov.uk/catalogue/PUB14866>

Release of dementia recorded diagnoses data for April 2014 to February 2015 on 17<sup>th</sup> March 2015

<http://www.hscic.gov.uk/pubs/qofdemapr14feb15>

This release appends data for the month of March 2015 to the available data.

## Dementia Strategy 2009

The Department of Health (DH) launched the National Dementia Strategy in 2009

(<https://www.gov.uk/government/publications/living-well-with-dementia-a-national-dementia-strategy>). The strategy highlighted the issue of under-diagnosis; data from 2007 quoted in the strategy estimated that only one third of people with dementia received a formal diagnosis<sup>1b</sup>. One

of the key objectives of the dementia strategy was:

**Good-quality early diagnosis and intervention for all.** *All people with dementia to have access to a pathway of care that delivers: a rapid and competent specialist assessment; an accurate diagnosis sensitively communicated to the person with dementia and their carers; and treatment, care and support provided as needed following diagnosis. The system needs to have the capacity to see all new cases of dementia in the area.*

## The Prime Minister's Dementia Challenge 2012

Prime Minister David Cameron launched the Dementia Challenge in 2012

(<http://dementiachallenge.dh.gov.uk/>), to build on the 2009 National Dementia Strategy. A key component of the challenge is to improve diagnosis rates for dementia; so that more patients

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<sup>1a</sup> Dementia is defined as specified in v 29.0 of QOF

<sup>1b</sup> NAO (2007). Improving services and support for people with dementia. London: TSO.  
(<http://www.nao.org.uk/report/improving-services-and-support-for-people-with-dementia/>)

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suffering from dementia are given a formal diagnosis so that they can receive the appropriate care and support.

NHS England has an ambition to increase the dementia diagnosis rate to 67 per cent by March 2015 (<http://www.england.nhs.uk/wp-content/uploads/2013/12/5yr-strat-plann-guid-wa.pdf>). By this measure two thirds of the estimated number of people with dementia would receive a formal diagnosis and access to appropriate post-diagnosis support.

## **NHS Mandate 2014-15**

*The Government's goal is that the diagnosis, treatment and care of people with dementia in England should be among the best in Europe.*

*The objective is for NHS England is to make measurable progress towards achieving this by March 2015, in particular ensuring timely diagnosis and best available treatment for everyone who needs it, including support for carers.*

*NHS England have agreed a national ambition for diagnosis rates that by 2015 two-thirds of the estimated number of people with dementia in England should have a diagnosis, with appropriate post-diagnosis support. Better dementia diagnosis will improve the lives of people with the condition and give them, their carers and professionals the confidence that they are getting the care and treatment they need. NHS England should work with CCGs to support local proposals for making the best treatment available across the country.*

To support monitoring of progress for this ambition, DH and NHS England requested that the Health and Social Care Information Centre (HSCIC) provide monthly updates to the QOF dementia register data. Data for April 2014 to February 2015 were published on 17<sup>th</sup> March (<http://www.hscic.gov.uk/pubs/qofdemapr14feb15>). Data for previous months have not been updated or revised, they are simply re-issued (see also [3.1 What are the plans for releasing data for other months?](#)).

## **2.0 What data are included in this release?**

This report does not contain any summarised data or analysis. Data are provided at practice level in Annex 1. 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.

### **List size (for each month)**

This is the number of patients registered at the practice as at the end of the specified month.

### **Dementia register (for each month)**

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.

## 2.1 Which practices are included in the dataset?

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>2</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.

All practices had the opportunity to opt out of the extract and some practices chose to do this. Where a practice opted out it was removed from the estate as being unavailable for extraction.

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. Where GPES did not manage to collect the data during the extract window, the practice code will be listed but no data will be shown. The data fields show ‘.’ for these 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).

**Table 1.0 National coverage of GPES extracts**

	Apr-14		May-14		Jun-14		Jul-14		Aug-14		Sep-14		Oct-14		Nov-14		Dec-14		Jan-15		Feb-15		Mar-15	
	Practices	Percent of practices	Practices	Percent of practices	Practices	Percent of practices	Practices	Percent of practices	Practices	Percent of practices	Practices	Percent of practices	Practices	Percent of practices	Practices	Percent of practices	Practices	Percent of practices	Practices	Percent of practices	Practices	Percent of practices	Practices	Percent of practices
Total estate	7,946	-	7,946	-	7,944	-	7,926	-	7,926	-	7,833	-	7,807	-	7,793	-	7,797	-	7,781	-	7,776	-	7,776	-
Opting out	145	1.8	145	1.8	145	1.8	145	1.8	145	1.8	152	1.9	151	1.9	149	1.9	128	1.6	122	1.6	117	1.5	86	1.1
Extract cohort	7,801	-	7,801	-	7,799	-	7,781	-	7,781	-	7,681	-	7,656	-	7,644	-	7,669	-	7,659	-	7,659	-	7,690	-
No data collected	600	7.7	724	9.3	532	7.6	551	7.1	611	7.9	496	6.5	352	4.6	451	5.9	380	5.0	405	5.3	461	6.0	204	2.7
Data collected	7,201	92.3	7,077	90.7	7,207	92.4	7,230	92.9	7,170	92.1	7,185	93.5	7,304	95.4	7,193	94.1	7,289	95.0	7,254	94.7	7,198	94.0	7,486	97.3

The cohorts change over time, generally this is because practices will have opened and closed in the intervening period. For the March extract the most significant impact on the change in the cohort is refinements to the total estate as described above.

<sup>2</sup> Technology Reference data Update Distribution - <https://isd.hscic.gov.uk/trud3/user/guest/group/0/home>

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

The annual QOF publication was released on 28<sup>th</sup> 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 in 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 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](#). 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.

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

This release adds data for March 2015 to those previously published for April 2014 to February 2015. The data were extracted during April 2015 and this is the last planned extract by the HSCIC in the current format.

Data was published at regular monthly intervals during 2014/15 (February data published in March, March data published in April), continuing the time-series until all data for 2014/15 were released.

No decision has been taken on continuing these releases into 2015/16.



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## 4.0 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:

### 4.1 Recorded prevalence

Dementia register data are a component of the QOF<sup>3</sup> (see [Overview of the Quality and Outcomes Framework](#)). For 2013/14, 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>4</sup>. No personal identifiable data (PID) are collected through this mechanism; they are simply an aggregate number of patients with a diagnosis at each practice.

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

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

*Recorded dementia prevalence =*

*(Number of patients on dementia register / Number of patients registered at practice) x 100*

**Note that we have not calculated recorded prevalence in this release. The release includes numbers on each practice dementia register and the number of patients registered at each practice.**

### 4.2 Estimated prevalence

In 2007 the Alzheimer's Society produced estimated prevalence figures for dementia. These figures are based on a Delphi consensus exercise, and are viewed as the most authoritative to date (see the Dementia UK report).

The Dementia UK<sup>5</sup> 2007 report contains estimates of late onset dementia prevalence rates (i.e. how many people have dementia as a proportion of the population in that age band) by 5 year age bands from age 30 to 95+. These rates are available by gender and as a weighted average for all persons. Estimates of dementia were calculated for the UK and in each local authority (or equivalent) in each of the UK countries. As these estimates are based on research evidence, they are not updated on a routine basis. The Alzheimer's Society is currently reviewing these data, with a view to provide updated estimated prevalence data.

**The HSCIC does not produce “estimated prevalence” data, and this data extract does not include these data**

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<sup>3</sup> <http://www.nhsemployers.org/your-workforce/primary-care-contacts/general-medical-services/quality-and-outcomes-framework>

<sup>4</sup> <http://www.hscic.gov.uk/qofextractspecs>

<sup>5</sup> [http://www.alzheimers.org.uk/site/scripts/download\\_info.php?fileID=2](http://www.alzheimers.org.uk/site/scripts/download_info.php?fileID=2)



## 4.3 Diagnosis rate

Not all people who have dementia currently have a diagnosis. Diagnosis rate refers to the number of people who have received a diagnosis as a percentage of those estimated to have the condition.

Diagnosis rate is used in the NHS Outcomes Framework<sup>6</sup> (indicator 2.6i): *Estimated diagnosis rate for people with dementia*. To calculate diagnosis rate; Estimated prevalence data are applied to population estimates (sourced from the Office of National Statistics). The number of patients on QOF dementia registers is then divided by this figure:

*Dementia diagnosis rate =*

*Number of patients on dementia register / (Estimated prevalence x Population estimate)*

**The dementia diagnosis rate is the focus of the 67 per cent ambition. Diagnosis rate is not provided or calculated in this report. See [Uses and usage](#) for more information.**

Further details on the indicator calculation and latest available diagnosis rates are available at:

HSCIC indicator specification

[https://indicators.ic.nhs.uk/download/Outcomes%20Framework/Specification/NHSOF\\_Domain\\_2\\_S\\_V2.pdf](https://indicators.ic.nhs.uk/download/Outcomes%20Framework/Specification/NHSOF_Domain_2_S_V2.pdf)

HSCIC indicator portal <https://indicators.ic.nhs.uk/webview/>

Public Health Outcomes Framework tool <http://www.phoutcomes.info/public-health-outcomes-framework#gid/1000044/pat/6/ati/102/page/6/par/E12000004/are/E06000015>

## 5.0 Caveats & constraints

### Monthly register data

The dementia extracts are the first time that monthly counts of patients on a QOF disease register have been collected using GPES and provided on a regular basis. The code cluster used to define dementia matches the established QOF code cluster, and the extraction definitions have been tested with the GP system suppliers, which provides confidence with the data. Consistency and comparability of data over time will only be apparent with subsequent extractions.

### Coverage

As discussed previously, there are instances where data for a practice is not available, either because the practice opted out, or where data was not collected during the extraction window. A practice included in a previous dataset may not be present in these data because it has since closed, similarly new practices may have opened in during this time.

### Practice list sizes

Practice list sizes provided are those extracted from GPES as part of the dementia sub-set. These may be different to those available from other sources. These data were used rather than Exeter data as they were considered more appropriate for any prevalence and coverage calculations as they match the extraction date of the dementia register data. They will provide a regularly updated denominator for both prevalence and coverage calculations for each monthly extract.

For the September data, there were concerns regarding the accuracy of practice list size data. We suspect that for some practices, the extracted data significantly over-reported patient list sizes

<sup>6</sup> <https://www.gov.uk/government/publications/nhs-outcomes-framework-2014-to-2015>

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when compared with previous months. For the affected practices (136 were identified), we used the August list size previously extracted, in place of the September list size. For these practices, the patient list size is shown in red on the accompanying spreadsheet. In identifying this issue, there is potential that the same issue affects patient list size data for previous months (April to August), though we believe this to have less of an overall impact, affecting fewer practices. Previously published data have not been changed.

The patient list size for October onwards data does not appear to contain any new issues. The HSCIC will continue to check extracted list sizes against list size data from alternative sources. We do not believe that dementia register data (the number of patients diagnosed with dementia) are affected.

## 5.1 Uses and usage

As described in the definitions section, numbers of patients on dementia registers are a component of both [recorded prevalence](#) and [diagnosis rate](#). These data will be used by DH and NHS England to monitor diagnosis rates at individual practice and CCG level, to inform targeting of resources and improvement activity to work toward the 2015 ambition.

More detailed QOF information for 2012/13, and QOF information from previous years, has been published by the Health and Social Care Information Centre at <http://www.hscic.gov.uk/qof>

## 6.0 Data quality statement

### Data source & coverage

Information in this bulletin was derived from the Calculating Quality Reporting Service (CQRS)<sup>7</sup> a national system developed by the HSCIC. CQRS uses data extracted from general practices via the General Practice Extraction Service (GPES)<sup>8</sup>. GPES data were extracted as part of the QOF subset 2014/15 dementia data extraction (<http://www.hscic.gov.uk/article/4863/Quality-and-Outcomes-Framework-subset-2014-15-dementia-data-extraction>).

### Accuracy

Issues were identified with practice list size data reported for some practices in September. This is described in more detail under [Practice list sizes](#).

The accuracy of these data depends on:

Clinical case finding by GPs – numbers of patients on QOF dementia registers depends on people with dementia being diagnosed.

Clinical coding – when patients are diagnosed with dementia the quality of QOF data about people with dementia depends on the GP practice maintaining accurate, and coded, clinical records and using the codes as defined in QOF business rules.

As QOF information is used to calculate payments to GP practices means that practices' clinical information system suppliers deliver systems to maximise QOF data recording and quality of coding. GP practices are similarly incentivised to ensure that patient records are accurate and up to date so that appropriate QOF information is collected by GPES to calculate practice payments.

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<sup>7</sup> <http://systems.hscic.gov.uk/cqrs>

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

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## Relevance

This report looks at Quality Outcomes Framework (QOF) recorded dementia diagnoses for each month from April 2014 to March 2015.

Prime Minister David Cameron launched the Prime Minister's Dementia Challenge in 2012 (<http://dementiachallenge.dh.gov.uk/>). A key component of the challenge is to improve diagnosis rates for dementia; so that more patients with dementia are given a formal diagnosis so that they can receive the appropriate care and support.

NHS England has an ambition to increase the dementia diagnosis rate to 67 per cent by March 2015 (<http://www.england.nhs.uk/wp-content/uploads/2013/12/5yr-strat-plann-guid-wa.pdf>). By this measure two thirds of people with dementia would receive a formal diagnosis. DH and NHS England have requested that the HSCIC provides regular updates to dementia register data to assist with monitoring progress toward this ambition.

## Timeliness & Punctuality

The data for this report relate to the last day of March 2015. They were extracted during early April 2015 and will be published on 16<sup>th</sup> April 2015.

## Coherence & Comparability:

QOF information is collected primarily to support QOF payment calculations under GP contracts, and that data collection from practices is (for clinical information) based on detailed coded business rules.

Information on QOF clinical registers may not precisely match disease definitions used by epidemiologists.

It is extremely important to take account of QOF definitions (including coding contained in QOF business rules) before comparing QOF information with other data sources – for example comparing QOF disease prevalence with expected prevalence rates (based on public health models).

Specific issues and caveats concerning the interpretation of these data are contained in the bulletin (see [3.0 Measures associated with dementia](#))

## Accessibility & Clarity

The report is accessible via the HSCIC internet as PDF documents. Local level information is provided in Excel format.

## Performance, Cost & Respondent Burden:

This collection used a specific GPES extract of data. There is no additional burden on practices in providing these data, and practices had the option to opt out of the extract. The data extracts were carried out by GPES, working closely with system suppliers.

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## **Confidentiality, Transparency and Security**

Published information is derived from data collected via CQRS and GPES.

QOF data are subject to risk assessments around disclosure. However, no patient identifiable data is available in these extracts. Standard HSCIC protocols around information governance are followed in the production of this publication.

## **List of Annexes**

**Annex 1 – Quality Outcomes Framework (QOF) Recorded Dementia Diagnoses – April 2014 to March 2015**

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**Published by the Health and Social Care Information Centre  
Part of the Government Statistical Service**

**Responsible Statistician**

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978-1-78386-373-0

This publication may be requested in large print or other formats.

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