



Health & Social Care
Information Centre

Data Provision Notice

Recorded Dementia Diagnoses 2016-17

For general practices in England

Notified 18/03/2016



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These data are being collected on behalf of NHS England to help ensure that there is an accurate, national count of the numbers of patients diagnosed with dementia so that national and local initiatives can respond appropriately and monitor change. The General Practice Extraction Service (GPES) will extract the data on a monthly basis.

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Background

The [Health and Social Care Act 2012 \(the Act\)](#) gives the Health and Social Care Information Centre (HSCIC) statutory powers, under [section 259\(1\) of the Act](#), to require data from health or social care bodies or organisations who provide health or adult social care in England, where it has been Directed to establish an information system by the Department of Health (DH) (on behalf of the Secretary of State) or NHS England.

When a direction is received, the HSCIC can issue a Data Provision Notice to the appropriate providers of the required data who are then legally required, under [section 259\(5\) of the Act](#), to provide the data in the Form, Manner and Period specified below.

The data, as specified by the HSCIC in this published Data Provision Notice, is required to support a direction from NHS England to the HSCIC. Therefore, organisations that are in scope of the notice are legally required, under [section 259\(5\) of the Act](#), to provide the data in the Form, Manner and Period specified below.

Purpose of the collection

NHS England need specific Recorded Dementia Diagnoses data to support the [National Dementia Strategy](#) and the [Prime Minister's challenge on dementia 2020](#).

An ambition to increase the rate of dementia diagnosis has been agreed by the NHS England and is specified in the [NHS mandate](#).

To help monitor this ambition, the HSCIC collected data on a monthly basis from general practice systems during 2014-15 to produce an aggregated number of people at each general practice with a diagnosis of dementia, as well as the general practice's total registered population. These data are published on the HSCIC website; an example of this can be found [here](#).

For 2015-16, the requirement was extended to include dementia diagnoses data broken down by age and gender, in order to determine age and gender differences in diagnosis rates. These data are published on the HSCIC website and can be found [here](#).

The 2015-16 data collection will continue unchanged for 2016-17 in order to support NHS England and the above strategies.

Benefits of the collection

The Department of Health (DH) launched the [National Dementia Strategy](#) in 2009. The strategy highlighted the potential issue of under-diagnosis of people with dementia. This data collection will be used by NHS England in order to monitor diagnosis rates for dementia during 2016-17.

Legal basis for the collection, handling, publication and dissemination

The HSCIC has been directed by NHS England under [section 254 of the Act](#); to establish and operate a system for the collection and analysis of the information specified for this service. A copy of the Directions was [approved by the HSCIC Board on 15 July 2015](#)¹.

This information is required by the HSCIC under [section 259\(1\) of the Act](#).

In line with [section 259\(5\) of the Act](#), all general practices in England must comply with the requirement and provide information to the HSCIC in the Form, Manner and Period specified in this Data Provision Notice.

This Notice is issued in accordance with the [procedure published](#) as part of the HSCIC duty under [section 259\(8\) of the Act](#).

Persons consulted

Following receipt of a direction to establish a system to collect Recorded Dementia Diagnoses data the HSCIC has, as required under [section 258 of the Act](#), consulted with the following persons:

- The Joint General Practice Information Technology Committee (JGPITC) with membership from both the British Medical Association (BMA) and the Royal College of General Practitioners (RCGP).
- Co-chairs of the JGPITC, who were content with this collection, on behalf of their members.
- The Standardisation Committee for Care Information (SCCI), which included representatives from the Allied Health Professionals Federation, Data Standards Panel, Department of Health (DH), Medicines and Healthcare products Regulatory Agency (MHRA), Monitor, NHS Employers, NHS England, NHS Northern Ireland, Professional Records Standards Body (PRSB), techUK and the HSCIC. SCCI accepted the 2016-17 Recorded Dementia Diagnoses data collection².

Scope of the collection

Under [section 259\(1\) of the Act](#), this Notice is served on general practices in accordance with the procedure published as part of the HSCIC duty under [section 259\(8\) of the Act](#).

Under [section 259\(5\) of the Act](#), the organisation types specified in the above Scope must comply with the Form, Manner and Period requirements below:

¹ The Directions for the Recorded Dementia Diagnoses 2015-16 data collection have been extended to cover the Recorded Dementia Diagnoses 2016-17 data collection.

² The Recorded Dementia Diagnoses 2016-17 data collection was discussed at the SCCI meeting on 24 February 2016; the minutes of this meeting can be found at: <http://www.hscic.gov.uk/isce/scci-secretariat/meetings>

Form of the collection

This data collection will not involve collecting patient level information. Instead, data at general practice level (i.e. aggregated counts of patients broken down by general practice) will be collected.

This data collection is aggregated data specifying the number of people at each general practice with a diagnosis of dementia broken down by age and gender, as well as the number of the general practice's total registered population. The aggregated data required are based on Practice List Size Attribute and Dementia Indicator DEM002 of the Dementia Ruleset elements of the [QOF business rules v32.0](#) published by the HSCIC.

The following items are included in this data collection:

- Number of patients who have a diagnosis of dementia for each general practice in England at the end of each calendar month for the financial year 2016-17. The codes used to define dementia are those used in the [QOF business rules v32.0](#).
- The data to be collected in gender categories: Male, Female, and Unknown/Not Specified.
- The data to be collected in age categories: 0-29; 30-34; 35-39; 40-44; 45-49; 50-54; 55-59; 60-64; 65-69; 70-74; 75-79; 80-84; 85-89; and 90+.
- The total number of patients registered with the general practice.

Manner of the collection

Data will be collected via the General Practice Extraction Service (GPES), which will involve the appropriate data being automatically extracted from general practices' clinical IT systems. The [HSCIC GP Collections webpage](#) provides further information on this service.

General practices will receive an offer to accept the Recorded Dementia Diagnoses 2016-17 data collection on the Calculating Quality Reporting Service (CQRS) system. This offer should be accepted by all general practices.

Data Quality

When patients are diagnosed with dementia the quality of the data collected by the HSCIC depends on the general practice maintaining accurate, and coded, clinical records and using the codes as defined in the [QOF business rules v32.0](#) for this collection.

The number of patients registered with each practice will be collected. The HSCIC will compare these data with information from a routine national collection of general practice registration data and if the list sizes vary this will be investigated prior to publication.

In addition the HSCIC will investigate unexpected variations in data between months prior to publication. The HSCIC will also provide general practices with the opportunity to download and view the data that has been extracted for their practice prior to publication.

Period of the collection

Data will be collected on a monthly basis until the end of the financial year 2016-17.

The [HSCIC GP Collections Bulletin](#) will provide details of when this data collection will take place. General practices are advised to [register to receive this e-bulletin](#) if they have not already done so.

Further information and support

The [HSCIC GP Collections webpage](#) provides further information about how primary care data are collected by the HSCIC.

If you have any queries in relation to GPES or this Recorded Dementia Diagnoses 2016-17 data collection, please contact the HSCIC Contact Centre via enquiries@hscic.gov.uk with 'Data Provision Notice: Recorded Dementia Diagnoses 2016-17' in the subject line, or telephone 0300 303 5678.

Burden of the collection

Steps taken by HSCIC to minimise the burden of collection

The HSCIC has sought to minimise the burden on general practices by using existing data extract technology, rather than requesting information in another format which may be more burdensome to process.

In seeking to minimise the burden it imposes on others, in line with [section 253\(2a\) of the Act](#) and [section 265\(3\) of the Act](#), the HSCIC has an assessment process to validate and challenge the level of burden incurred through introducing new information standards, collections and extractions.

This assessment is carried out by the [Burden Advice and Assessment Service \(BAAS\)](#) who carry out a Detailed Burden Assessment and report findings and recommendations, as part of the overarching [Standardisation Committee for Care Information \(SCCI\)](#) process. The Committee oversees the development, assurance and acceptance of information standards, data collections and data extractions for the health and social care system in England.

Detailed burden assessment findings

This collection uses GPES, which imposes minimal burden on general practices.

A survey of subject matter experts was considered sufficient to assess the burden for providers of data.

No concerns were raised by the BAAS survey.

BAAS maintain and publish a central register of assessed data collections and extractions, including burden assessment detail relating to all national collections. Further information about the collection and estimated costs can be viewed from this register.

Assessed costs

The associated burden of the data collection is:

Burden on providers	£567k	2 minutes per month for 7,800 general practices.
Set up costs for the data collection	£0k	There are no set up costs as this collection is continuing unchanged from the 2015-16 collection.
Other costs of the data collection	£144k	Costs for general practice system suppliers and the HSCIC to extract and process the data.

Help us to identify inappropriate collections

BAAS offer a Data Collections Burden Reduction Service, which is a simple and confidential way to allow data providers to refer data collections they feel would benefit from further scrutiny.

Visit the [BAAS website](#) for more details and information on [how to refer a collection](#).

For further information

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