

# Data Provision Notice

## For Dementia Data 2016-17

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**Information and technology**  
**for better health and care**

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## Background

The Health and Social Care Act 2012 (the Act) gives the Health and Social Care Information Centre, also known as as [NHS Digital](#) and hereafter referred to by this name, 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.

The data, as specified by NHS Digital in this published Data Provision Notice, is required to support a Direction from NHS England to NHS Digital. 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 and manner specified below.

## Purpose of the collection

NHS England requires NHS Digital to collect dementia data in order to support the [Prime Minister's challenge on dementia 2020](#)<sup>1</sup> and the [2016-17 General Medical Services \(GMS\) contract](#)<sup>2</sup>.

The Prime Minister's challenge on dementia 2020 builds on the initial [Prime Minister's challenge on dementia](#)<sup>3</sup>. A key component of this initial challenge was to improve dementia diagnosis rates so that more patients suffering from dementia would be given a formal diagnosis and therefore receive the appropriate care and support.

The Prime Minister's challenge on dementia 2020 highlighted the importance of improving the dementia diagnosis rates in Black, Asian and Minority Ethnic (BAME) groups as evidence suggests that dementia diagnosis rates in these groups and seldom heard communities are particularly poor. This challenge also identified the need for all patients diagnosed with dementia to be given the opportunity for advanced care planning early in the course of their illness.

The facilitating timely diagnosis and support for people with dementia enhanced service ceased on 31 March 2016. In stopping this service, it was agreed under the 2016-17 GMS contract that GPs should continue to perform dementia assessments where clinically appropriate and that these data should continue to be collected. This is required to demonstrate that patients are receiving the appropriate care (including referral to memory clinics) where necessary.

The Dementia Data 2016-17 collection builds on the [2015-16 and 2016-17 Recorded Dementia Diagnoses collections](#)<sup>4</sup>, which involved collecting dementia diagnoses data broken down by age and gender. These data will continue to be collected in the Dementia Data 2016-17 collection but further dementia diagnoses data broken down by ethnicity group, as well as data on dementia care plans, dementia assessments and referral to memory clinics, will also be collected. This will support the Prime Minister's challenge on dementia 2020 and the 2016-17 GMS contract.

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<sup>1</sup> <https://www.gov.uk/government/publications/prime-ministers-challenge-on-dementia-2020>

<sup>2</sup> <http://www.nhsemployers.org/your-workforce/primary-care-contacts/general-medical-services>

<sup>3</sup> <https://www.gov.uk/government/publications/prime-ministers-challenge-on-dementia>

<sup>4</sup> <http://digital.nhs.uk/qofdementia>

By combining the 2016-17 Recorded Dementia Diagnoses collection with aspects of the previous dementia enhanced service and the additional data that NHS England wish to collect, NHS Digital and NHS England aim to reduce the workload, bureaucracy and burden placed on general practices and Regional Local Offices. This collection also aims to improve the collection efficiency and reduce costs; both the burden costs placed on general practices and the actual costs of setting up and running this collection.

## Benefits of the collection

This data collection will be used by NHS England to monitor diagnosis rates for dementia during the period that the data are collected. Collecting dementia diagnosis data broken down by age and gender, as well as ethnicity group, will allow NHS England to monitor dementia diagnoses rates at a more granular level.

Collecting data on dementia care plans, dementia assessments and referral to memory clinics will allow NHS England to demonstrate where patients are receiving the appropriate care where necessary.

## Legal basis for the collection, analysis, publication and dissemination

NHS Digital was 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 the 2015-16 Recorded Dementia Diagnoses collection or any subsequent amended version of this collection<sup>5</sup>. This Direction was [accepted by the NHS Digital Board on 15 July 2015](#)<sup>6</sup>; the signed copy is published on the [gov.uk website](#)<sup>7</sup>.

**This information to be collected is required by NHS Digital under section 259(1) of the Act. The Dementia Data 2016-17 collection will not involve collecting confidential / personal information.**

In line with section 259(5) of the Act, all general practices in England must comply with the requirement and provide information to NHS Digital 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 NHS Digital duty under section 259(8) of the Act.

Under section 260 of the Act, NHS Digital will publish all of the information it obtains from complying with this Direction.

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<sup>5</sup> The Direction for the 2015-16 Recorded Dementia Diagnoses collection was extended to cover the 2016-17 Recorded Dementia Diagnoses collection and the Dementia Data 2016-17 collection.

<sup>6</sup> [https://www.gov.uk/government/uploads/system/uploads/attachment\\_data/file/444303/20150715\\_HSCICBoardPapers\\_Part1\\_Public.pdf](https://www.gov.uk/government/uploads/system/uploads/attachment_data/file/444303/20150715_HSCICBoardPapers_Part1_Public.pdf)

<sup>7</sup> [https://www.gov.uk/government/uploads/system/uploads/attachment\\_data/file/510125/Dementia\\_Directions\\_Oct\\_2015.pdf](https://www.gov.uk/government/uploads/system/uploads/attachment_data/file/510125/Dementia_Directions_Oct_2015.pdf)

## Persons consulted

Under section 258 of the Act, NHS Digital consulted with the appropriate persons before establishing the information system for Dementia Data 2016-17 collection. The consultees included:

- NHS England's Data Coordination Group and Data and Services Panel.
- The Standardisation Committee for Care Information (SCCI), which included representatives from the UK Data Standards Panel, the Department of Health, the Medicines and Healthcare products Regulatory Agency, the National Institute for Health and Care Excellence, NHS Employers, NHS England, NHS Improvement, NHS Northern Ireland, the Professional Records Standards Body (PRSB), techUK and NHS Digital<sup>8</sup>.

Following receipt of the Direction to establish a system to collect the 2015-16 Recorded Dementia Diagnoses data, NHS Digital consulted with the Joint General Practice Information Technology Committee (JGPITC), which included representatives from the British Medical Association (BMA) and the Royal College of General Practitioners (RCGP), and SCCI.

## Scope of the collection

Under section 259(1) of the Act, this Notice is served on all general practices in England in accordance with the procedure published as part of the NHS Digital duty under section 259(8) of the Act.

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

## 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.

For each general practice included in this data collection, NHS Digital will collect the following:

- A count of the total number of registered patients at the general practice.
- Counts of the number of patients with a dementia diagnosis in their clinical record broken down by age and gender. The following age and gender categories will be used:
  - Age (in years): 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+
  - Gender: Male, Female, and Unknown/Not Specified
- Counts on dementia assessments and referral to memory clinics.

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<sup>8</sup> The Dementia Data 2016-17 collection was assured by SCCI on 27 July 2016:  
<https://groups.ic.nhs.uk/SCCIDsupport/dashboard/SAC/SCCI2090-2058/2090-2058642016sac.pdf>

- Counts of the number of patients with a dementia diagnosis in their clinical record broken down by ethnicity group. The ethnicity groupings will be taken from the England and Wales 2011 census. There are 20 ethnicity groups in total (including 'Not stated' and 'Not specified').
- Counts on dementia care plans.

Patients will be defined as having a dementia diagnosis as per v35.0 of the Quality and Outcomes Framework (QOF) Dementia business rules, which will be published on the [NHS Digital website](#)<sup>9</sup>.

The [Dementia Data 2016-17 Primary Care Data Application Form](#)<sup>10</sup> contains full details of the data that will be collected.

## Manner of the collection

Data will be collected via the General Practice Extraction Service (GPES), which will involve the appropriate data being extracted from general practices' clinical IT systems. The [NHS Digital GP Collections webpage](#)<sup>11</sup> provides further information on this service.

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

## Period of the collection

Data will be collected on a monthly basis.

The first collection is scheduled to take place in November 2016 – this will cover data up to 31 October 2016. The collection will be reviewed at the end of the 2016-17 financial year to decide whether or not it will continue in its current form.

The [GP Collections Timetable 2016-17](#)<sup>12</sup> provides further details of when this data collection will take place. Please note that this timetable is a live document and is frequently edited to reflect changes to the GPES collection schedule; users are advised to check this regularly for updates.

## Data Quality

When patients are diagnosed with dementia the quality of the data collected by NHS Digital depends on the general practice maintaining accurate, and coded, clinical records and using the codes as defined in v35.0 of the QOF Dementia business rules.

The number of patients registered with each practice will be collected. NHS Digital 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.

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<sup>9</sup> <http://digital.nhs.uk/qof>

<sup>10</sup> <https://groups.ic.nhs.uk/SCCIDsupport/dashboard/SAC/SCCI2090-2058/2090-2058pcdaf.pdf>

<sup>11</sup> <http://systems.digital.nhs.uk/gpcollections>

<sup>12</sup> <http://systems.digital.nhs.uk/gpcollections/whatwecollect/timetable201617.pdf>

NHS Digital will investigate unexpected variations in data between months prior to publication. GPES also provides general practices with the opportunity to download and view the data that has been extracted for their general practice prior to publication.

## Further information and support

The [NHS Digital GP Collections webpage](#)<sup>11</sup> provides further information about how primary care data are collected by NHS Digital.

If you have any queries in relation to GPES or this Dementia Data 2016-17 collection, please contact the NHS Digital Contact Centre via [enquiries@nhsdigital.nhs.uk](mailto:enquiries@nhsdigital.nhs.uk) with 'Data Provision Notice: Dementia Data 2016-17' in the subject line, or telephone 0300 303 5678.

## Burden of the collection

### Steps taken by NHS Digital to minimise the burden of collection

NHS Digital 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 sections 253(2a) and 265(3) of the Act 2012, NHS Digital 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), which carries out a Detailed Burden Assessment and reports findings and recommendations, as part of the overarching 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 maintains and publishes a [central register of assessed data collections and extractions](#)<sup>13</sup>, including burden assessment detail relating to all national collections. Further information about the collection and estimated costs can be viewed from this register.

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<sup>13</sup> <http://digital.nhs.uk/article/5073/Central-Register-of-Collections>

## Assessed costs

The associated burden of the data collection per annum is:

Burden on providers	£413k	Based on 4 minutes of a manager's time per monthly collection for 7,800 general practices.
Set up costs for the data collection	£86k	Costs for setting up this collection on GPES and CQRS.
Other costs of the data collection	£144k	Costs for general practice system suppliers to extract the data.

## Help us to identify inappropriate collections

NHS Digital's Burden Advice and Assessment Service (BAAS) offers a Collection Referral Service which is a simple and confidential way to allow data providers to refer data collections they feel would benefit from further scrutiny.

For more details and information on how to refer a collection, please visit:  
<http://www.digital.nhs.uk/article/6183/Collection-Referral-Service>

More about the Burden Advice and Assessment Service can be found at:  
<http://digital.nhs.uk/baas>

**For further information**

**[www.digital.nhs.uk](http://www.digital.nhs.uk)**

**0300 303 5678**

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