hscic Health & Social Care Information Centre

Data Provision Notice

Collection of aggregated numbers of patients in England with a record of dementia diagnosis on their clinical record

For General Practices in England

The HSCIC is the trusted national provider of high-quality information, data and IT systems for health and social care

www.hscic.gov.uk

enquiries@hscic.gov.uk

@hscic

Executive Summary

Appropriate access to mental health services is an important priority for everyone involved with the NHS. It is essential that patients diagnosed with particular conditions, including dementia, and their carers have access to all the services they require. These data are being collected on behalf of NHS England (NHSE) and the Department of Health (DH) to help ensure that there is an accurate national count of the numbers of patients diagnosed so that national and local initiatives can respond appropriately and monitor increases. The national initiatives are being coordinated with information from the Alzheimer's Society.

Information Asset Owner:	Dave Roberts, Head of Primary Care Information
Version:	V2.0
Date of notification:	31/07/2015

Contents

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), to require data from health or social care bodies or organisations who provide health or adult social care in England.

The Department of Health (DH) (on behalf of the Secretary of State or NHS England (NHSE) may direct the HSCIC to establish a data collection.

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

The data, as specified by the HSCIC in this published Data Provision Notice, is required to support a direction from NHSE to the HSCIC. Therefore, organisations who 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

NHSE and DH need specific dementia diagnosis data to support the National Dementia Strategy and the Prime Minister's Dementia Challenge.

An ambition to increase the rate of dementia diagnosis has been agreed by the NHSE and is specified in the NHS mandate.

To help monitor this ambition, the HSCIC collected data on a monthly basis during 2014/15 from general practice systems to produce an aggregated number of people at each general practice with a diagnosis of dementia, as well as the 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 has been extended to include dementia diagnoses data broken down by age and gender, in order to determine age and gender differences in diagnosis rates.

The following are the data requirements:

- 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 2015/16. The codes used to define dementia are those used in the Quality Outcomes Framework (QOF) business rules v. 31

- 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 practice

Benefits of the collection

DH launched the National Dementia Strategy in 2009. The strategy highlighted the potential issue of under-diagnosis. This data will be used by NHSE and the DH to monitor diagnosis rates from dementia during 2015/16.

Legal basis for the collection, handling, publication and dissemination

The HSCIC has been directed by NHSE under Section 254 of the Health and Social Care Act 2012; 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 July 15, 2015.

Following receipt of a direction to establish a system for the collection of aggregated numbers of patients in England with a record of dementia diagnosis on their clinical record, the HSCIC has, as required under Section 258 (1) of the Health and Social Care Act 2012, consulted with the following:

- 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.

This information is required by the HSCIC under Section 259(1) of the Health and Social Care Act 2012.

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).

Scope of the collection

All general practices in England.

The HSCIC and NHSE will not receive any patient-level data. The HSCIC and NHSE will receive data aggregated at general practice level. An Information Governance assessment of this collection advised that the data extracted is non-identifiable and there is no requirement for fair processing under the Data Protection Act 1998.

The data collected will be published on the HSCIC website on a monthly basis starting in September 2015.

Form of the collection

This 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 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 2015-16 Business Rules v31 published by the HSCIC.

Manner of the collection

The collection will be made using the General Practice Extraction Service (GPES). Further details on GPES can be found at: http://systems.hscic.gov.uk/gpcollections.

Collections will be backdated to April 2015.

CQRS will be used to manage general practices' participation to this data collection. No information from this collection will be stored in the CQRS system.

General practices will receive an offer from HSCIC to participate in the data collection which is called 'QOF Subset Dementia 2015/16'.

The offer will appear in the message centre of the CQRS system and will be available in early August 2015. Further communications will be issued by the CQRS team. General practices should select "Yes" when they see the message asking to accept the service. They will then see a message confirming that they have accepted the offer and are participating in collections for the service.

Data will then be collected from participating practices on the data collection dates.

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 (v.31) 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. Further details will be made available prior to the first extraction in September 2015.

Further information;

- Acceptance of the SCCI2090-2058 Dementia Diagnosis Data Extract data collection was agreed at the June 2015 Standards Committee for Care Information (SCCI) meeting. Minutes of the meeting can be found at: http://www.hscic.gov.uk/isce/scci-secretariat/meetings
- HSCIC GP Collections service – for more information on the data collection dates and participation
- CQRS user guides – details of how to perform certain tasks on CQRS

Support:

If you have any queries in relation to this, please contact the HSCIC Contact Centre via enquries@hscic.gov.uk with 'Dementia Data Provision Notice' in the subject line, or telephone 0300 303 5678.

Period of the collection

Data will be collected every month until the end of the financial year 2015/16. The HSCIC GP Collections Service Bulletins will specify the data collection dates.

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) and 265 (3) of the Health and Social Care Act 2012, 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 (DBA) and report 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 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 viewed from this register.

Burden Advice and Assessment Service recommendations

The burden of this collection should be reviewed again if this extract is to continue beyond 2015/16.

Help us to identify inappropriate collections

The HSCIC Burden Advice and Assessment Service (BAAS) offer a Data Collections Burden Reduction Service (DCBR) 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.hscic.gov.uk/3939

More about the Burden Advice and Assessment Service can be found at:
http://www.hscic.gov.uk/baas

For further information

www.hscic.gov.uk

0300 303 5678

enquiries@hscic.gov.uk