

Data Provision Notice

Learning Disabilities Observatory

For general practices in England

Notified 12/04/2016



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The Learning Disabilities Observatory data collection will support the production of a range of primary care indicators covering care quality for people with a learning disability. This data collection is for Public Health England. The General Practice Extraction Service (GPES) will extract the data on an annual 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\(1b\) of the Act](#), to request data from health or social care bodies or organisations who provide health or adult social care in England.

Where the HSCIC is requested to establish and operate a system for the collection or analysis of information under [section 255 of the Act](#), the HSCIC can issue a Data Provision Notice to the appropriate providers of the requested data who may provide the data in the Form, Manner and Period specified below.

The data, as specified by the HSCIC in this published Data Provision Notice, are requested to support a request from Public Health England to the HSCIC. Therefore, organisations that are in scope of the notice are requested to provide the data in the Form, Manner and Period specified below.

Purpose of the collection

Research shows that people with learning disabilities have poorer health, and receive poorer healthcare, than people without learning disabilities¹. Legislation requires that public bodies, including providers of health and social care, monitor their performance in identifying and addressing these issues.

In 2008, an [Independent Inquiry into Access to Healthcare for People with Learning Disabilities](#) recommended that “all healthcare organisations, including the Department of Health (DH) should ensure that they collect the data and information necessary to allow people with learning disability to be identified by the health service and their pathways of care tracked.”

DH accepted this recommendation and responded by stating that they would ask the HSCIC to work with Public Health England for the Learning Disabilities Observatory.

The data are to support production of a range of primary care indicators covering care quality for people with a learning disability. The data will be used for the benchmarking and quality improvement of primary care provision for people with learning disabilities.

This data collection is for Public Health England, who will publish the data at Clinical Commissioning Group (CCG) level in collaboration with the HSCIC. The HSCIC's General Practice Extraction Service (GPES) will extract the data on an annual basis.

Benefits of the collection

The Learning Disabilities Observatory data collection is anticipated to result in the following benefits:

- Improved commissioning and delivery of healthcare for people with learning disabilities through wider awareness of the extent of problems and better information about local and national performance.

¹ Johan Elliott, Chris Hatton, Eric Emerson, (2003) "The Health of People with Learning Disabilities in the UK: Evidence and Implications for the NHS", Journal of Integrated Care, Vol. 11 Iss: 3, pp.9 - 17

- Effective equalities monitoring of access to healthcare for people with learning disabilities for primary care commissioners (currently NHS England Area Teams) and, more widely, NHS commissioners.
- Provision of information for local campaigning groups, such as [My Health My Choice](#), and national campaigning groups, such as [Mencap](#).
- Established levels of key physical health conditions in people with learning disabilities.

The [GPES Customer Benefits Plan for the Learning Disabilities Observatory](#) contains the full details of the anticipated benefits for this data collection.

Legal basis for the collection, handling, publication and dissemination

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

In line with [section 259\(4\) of the Act](#), all general practices in England are requested to provide information to the HSCIC.

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

Under [section 258 of the Act](#), the HSCIC has consulted with the following persons regarding this data collection:

- The Improving Health and Lives: Learning Disabilities Observatory, which is operated by Public Health England.
- The GPES Independent Advisory Group, which included representatives from the British Computer Society (BCS), British Medical Association (BMA), Royal College of General Practitioners (RCGP) and the HSCIC Information Governance team, as well as lay members and an ethicist. The GPES Independent Advisory Group recommended by majority vote that this data collection should proceed to extraction².
- 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. This data collection was presented to SCCI for information only³.

² The Learning Disabilities Observatory data collection was discussed at the GPES Independent Advisory Group meeting on 29 January 2015; the minutes of this meeting can be found at:
http://www.hscic.gov.uk/media/16400/GPES-IAG-Minutes-for-29-January-2015/pdf/GPES_IAG_minutes_29.01.15.pdf

³ The Learning Disabilities Observatory 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/scii-secretariat/meetings>

Scope of the collection

This Notice is served on general practices in England in accordance with the procedure published as part of the HSCIC duty.

General practices from the general practice system supplier The Phoenix Partnership (TPP) are not included in this data collection. Public Health England decided to proceed with this data collection without TPP general practices.

The organisation types specified above are requested to comply with this data collection in the Form, Manner and Period specified 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.

The data covers key health issues for people who are recorded by their GP as having a learning disability, and comparative data about a control group of patients who are not recorded by their GP as having a learning disability.

The data collection covers demography, health status, screening uptake, preventive interventions and prevalence and management of key health conditions. In a small number of key areas it also covers health outcomes.

The [GPES Customer Requirement Summary for the Learning Disabilities Observatory](#) contains full details of the data that will be collected; also refer to the [GPES Information Governance Assessment for the Learning Disabilities Observatory](#).

Manner of the collection

Data will be collected via 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 Learning Disabilities Observatory data collection on the Calculating Quality Reporting Service (CQRS) system. This offer should be accepted if a general practice wishes to participate in this data collection.

Data Quality

This collection will only involve data being collected from general practices' clinical IT systems; other systems maintained by general practices are out of scope.

GPES provides a data certification service, which tests whether the technical specification for a data collection is correctly defined. The general practice system suppliers must pass certification before the data are collected.

Data certification is used to reduce the risk of data quality issues, yet some issues may persist following certification. This is because the data collections will only be as good as the data inputs.

GPES also cannot give assurances that the returned data fully meet the key data quality principles of accuracy, completeness and timeliness.

Period of the collection

This data collection involves three annual data collections:

- The first data collection covers data from the 2014-15 financial year (i.e. from 1 April 2014 to 31 March 2015).
- The second data collection covers data from the 2015-16 financial year (i.e. from 1 April 2015 to 31 March 2016).
- The third data collection covers data from the 2016-17 financial year (i.e. from 1 April 2016 to 31 March 2017).

The first data collection took place in January 2016 and the second and third data collections will take place after the end date of the financial year in question (i.e. the 2015-16 data collection will take place after 31 March 2016 and the 2016-17 data collection will take place after 31 March 2017).

The [HSCIC GP Collections Bulletin](#) will provide details of when these 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 Learning Disabilities Observatory data collection, please contact the HSCIC Contact Centre via enquiries@hscic.gov.uk with 'Data Provision Notice: Learning Disabilities Observatory' 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](#) who carry out a Detailed Burden Assessment and report findings and recommendations, as part of the overarching [Standardisation Committee for Care Information](#) 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

There is minimal burden on general practices as the collection is automatically effected by the general practice system suppliers. Information required is routinely collected and recorded in general practice systems as part of the ongoing interaction between GPs and their patients.

Assessed costs

The associated burden of the data collection is:

Burden on providers	£10k	
Set up costs for the data collection	£23k	Learning Disabilities Observatory collection received costs.
Other costs of the data collection	£132k	Are costs for general practice system suppliers and the HSCIC to collect and process the data.

Help us to identify inappropriate collections

The HSCIC Burden Advice and Assessment Service 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 [Burden Advice and Assessment Service website](#) for more details and information on [how to refer a collection](#).

For further information

www.hscic.gov.uk

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