

Data Provision Notice

Learning Disabilities Data

Information Asset Owner: Dave Roberts

Version: 3.0

Published: 26 August 2020



Information and technology
for better health and care

Contents

Background	3
Purpose of the collection	3
Benefits of the collection	3
Legal basis for the collection, analysis, publication, dissemination and transparency	4
Persons consulted	5
Health and Social Care Bodies within the scope of the collection	6
Form of the collection	6
Manner of the collection	7
Period of the collection	8
Data quality	8
Burden of the collection	9
Steps taken by NHS Digital to minimise the burden of collection	9
Detailed burden assessment findings	9
Assessed costs	9
Appendix A: Specification	10

Background

The Health and Social Care Act 2012 (the **2012 Act**) gives the Health and Social Care Information Centre, now known as **NHS Digital**¹ and hereafter referred to by this name, statutory powers, under section 259(1)(a), to require data from health or social care bodies, or organisations that provide publicly funded health or adult social care in England, where it has been directed to establish an information system by the Secretary of State for Health and Social Care (**Secretary of State**) or NHS England.

The data, as specified by NHS Digital in this published Data Provision Notice (**DPN**)², 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(1)(a) of the 2012 Act, to provide the data in the form and manner specified below.

Purpose of the collection

NHS England has directed NHS Digital to collect and analyse data in connection with [the Learning Disabilities Observatories GPES Extract Data Collection Directions 2018](#). However, from August 2020 the collection is now known as the Learning Disabilities Data Extract (**LDD**). This is because the Learning Disabilities Observatory is no longer an organisation within Public Health England (PHE). This means the LDD programme of work has moved from PHE to NHS England and NHS Improvement (NHSE & NHSI).

Research shows that people with learning disabilities have poorer health, and receive poorer healthcare, than people without learning disabilities³. 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 and Social Care (DHSC) 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.” DHSC accepted this recommendation and work started on the data collection in support of this.

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 NHSE & NHSI. NHS Digital will publish the data at Clinical Commissioning Group (CCG) level.

Benefits of the collection

This data extraction was set up in 2015 and the data has been collected using the same format for financial years 2015-16, 2016-17, 2017-18 and 2018-19. A post implementation review has taken place resulting in improvements to all future data collections. This will be achieved through the:

- removal of a small number of indicators which are no longer required

¹ <https://digital.nhs.uk/>

² This DPN supersedes version 2.0 published in June 2018.

³ 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

- addition of a small number of indicators to capture additional key information (for example, in relation to prescription of medications)
- addition of a new age breakdown and count to support alignment of health check related counts with requirements of the associated Enhanced Service.

The majority of the new indicators facilitate the monitoring of the level of antipsychotic and antidepressant use in patients with learning disabilities. Research studies using General Practice data in the Clinical Practice Research Datalink indicate that prevalence of the use of both of these drugs in adults with learning disabilities is approximately 17%⁴. This is substantially in excess of the levels appropriate to treatment of mental health problems and is thought to arise from clinically inappropriate approaches to managing behaviour.

Other new indicators facilitate the comparison of the recorded prevalence of autism in patients with and without a diagnosis of a learning disability. They provide more accurate insights into the uptake of learning disability health checks.

[Appendix A](#) provides a link to the Specification where details of each data item to be extracted can be found.

The data is used to support improved commissioning and delivery of healthcare for people with learning disabilities. The key benefit NHSE & NHSI expects to achieve will be improved data which will provide a spur to improve the quality of healthcare for people with learning disabilities. This is expected to follow over a time span of four to five years with regular annual data collection and publication.

The LDD extract will enable NHSE & NHSI to:

- make information about the health and healthcare for people with learning disabilities more readily available and understandable
- undertake detailed secondary analyses of existing data sets to identify important new lessons for service improvement and development
- share the learning by working to ensure that key messages about best practice in providing healthcare for people with learning disabilities are widely understood
- improve available information by surveying data gaps and working to fill them.

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

Collection and Analysis

NHS Digital has been directed by NHS England under section 254 of the 2012 Act; for the collection and analysis of the information specified for this service. A copy of the [the Learning Disabilities Observatories GPES Extract Data Collection\) Directions 2018](#) is published here:

<https://digital.nhs.uk/about-nhs-digital/corporate-information-and-documents/directions-and-data-provision-notice/nhs-england-directions/establishment-of-information-systems-for-nhs-services-the-learning-disabilities-observatories-gpes-extract-data-collection-direction-2018>

⁴ . Glover G., Williams R., Branford, D., Avery, R., Chauhan, U., Hoghton, M. and Bernard, S. (2015) Prescribing of psychotropic drugs to people with learning disabilities and/or autism by general practitioners in England. Public Health England gateway number 2015105. Published online at http://webarchive.nationalarchives.gov.uk/20160704152031/https://www.improvinghealthandlives.org.uk/publications/1248/Prescribing_of_psychotropic_medication_for_people_with_learning_disabilities_and_autism

[Appendix A](#) provides a link to the Specification where details of each data item to be extracted can be found.

The National Data Opt-Out will not apply to the extraction of data to NHS Digital for this collection as this is an aggregate data collection.

This Notice is issued in accordance with the procedure published as part of NHS Digital duty under section 259(8) of the 2012 Act.

Publication

This data collection is for NHSE & NHSI. NHS Digital will continue to [publish the data](#) at Clinical Commissioning Group (CCG) level.

NHS Digital processes and publishes the data and information collected. Health and Care of People with Learning Disabilities publications may be found here: <https://digital.nhs.uk/data-and-information/publications/statistical/health-and-care-of-people-with-learning-disabilities>.

All information that is published will be published in accordance with the [Code of Practice for Statistics](#).

NHS Digital will receive data aggregated at General Practice level. The published information which will be used by NHSE & NHSI will contain data further aggregated at CCG level, reported against a range of indicators, in most cases split by age and gender categories which are:

- gender categories: male or female
- age categories grouping A: 0 – 9, 10 – 17, 18 – 24, 25 – 34, 35 – 44, 45 – 54, 55 – 64, 65 – 74, 75 and over
- age categories grouping B: 0 – 9, 10 – 13, 14 – 17, 18 – 24, 25 – 34, 35 – 44, 45 – 49, 50 – 54, 55 – 59, 60 – 64, 65 – 69, 70 – 74, 75 and over.

Dissemination

NHSE & NHSI use the published data. Therefore, a Data Sharing Agreement is not required.

Transparency

NHS Digital will disclose in its [Data Release Register](#) the organisations to whom it disseminates the data obtained through this DPN and the purposes of the dissemination.

The transparency notice for this collection can be found here: <https://digital.nhs.uk/about-nhs-digital/our-work/keeping-patient-data-safe/gdpr/gdpr-register/learning-disability-observatory>

Persons consulted

NHS Digital has, as required under section 258 of the 2012 Act, consulted with the following organisations:

- Improving Health and Quality: Learning Disability Programme, which is operated by NHSE & NHSI
- British Medical Association (BMA)
- Royal College of General Practitioners (RCGP)

- NHS Digital Information Governance team, The Data Coordination Board (**DCB**)⁵, which includes representatives from the Department of Health and Social Care (**DHSC**), NICE, NHS England and NHS Improvement, PHE, Care Quality Commission (**CQC**), Local Government Association (**LGA**), Health Education England (**HEE**), Health Research Authority (HRA), Association of Directors of Adult Social Services (**ADASS**) and NHS Digital.

Health and Social Care Bodies within the scope of the collection

Under section 259(1)(a) of the 2012 Act, this Notice is served in accordance with the procedure published as part of the NHS Digital duty under section 259(8) on the following persons:

- General Practices in England whose system suppliers are in scope of this data collection:
 - EMIS
 - Vision
 - Microtest

Under section 259(1)(a) and (5) of the 2012 Act the organisation types specified in the above Scope must comply with the Form, Manner and Period requirements below.

Form of the collection

GPES business rules will be provided to General Practice System Suppliers (GPSS) to set out the scope of the collection. The GPSS develop the extract in accordance with the business rules.

Once the extract is developed, GPES will be used to schedule and manage the collection and onward processing of the data into Data Processing Service (DPS). GPES is an established mechanism to schedule, extract and deliver General Practice data from GPSS clinical systems. For the purposes of the LDD collection, it is made up of three key components:

- GPDC: The GP Data Collector is the solution operated by the NHS Digital's Data Services Alliance team. It will send requests for data to the GPSS solutions. It is located on SUS+ physical infrastructure hosted in the Crown Hosting datacentres
- GPET-E: The GP Extraction Tool-Extractor is the GPSS solution used to extract the data from the clinical system on receipt of the request from the GP Data Collector. The resulting data files are sent to the NHS Digital DPS MESH mailbox
- MESH: Message Exchange for Social Care and Health is the secure transport mechanism used to transport the data from the GPET-Es to NHS Digital. Data files are stored on MESH in accordance with MESH's 30-day retention policy and are then deleted from MESH.

⁵ The Data Coordination Board (DCB) – a sub board of the system-wide Digital Delivery Board (DDB), the DCB acts with delegated authority from the DDB and directly from the Secretary of State as the main governance route through which all data collection requirements are agreed, and priorities assigned.

DPS is the platform where the data will be processed and stored. NHS Digital uses Amazon Web Services (AWS) to host the data located within the UK, consequently AWS is a data processor for all data stored on DPS and NHS Digital has GDPR Article 28(3) compliant contracts in place with AWS.

The Customer Requirement Output (CRO) is the data that GPSS extract from General Practice clinical systems and submit to GPES. The CRO is based on the business rules (referred to as the 'Extraction Requirement') that GPES circulates to GPSS.

The data set will be contained in a single CRO file per GP practice, made up of five attributes: General Practice code, Indicator ID, Indicator name (which includes gender category, Age category) and Count. This will contain aggregated data for the range of indicators of this requirement.

NHS Digital's GP Data Collector System is used to request, collect, and process data from each GPSS and deliver it to the intended location, the Data Management Service (DMS or CQRS). GP Data Collector is hosted by the Data Delivery Centre (DDC) on the Secondary Uses Service (SUS)+ infrastructure. For this customer requirement, the GP Data Collector System will not undertake any transformation on the CRO. These data will be automatically deleted within 14 days of delivery to DMS. DMS will then retain the resulting CRO files containing data at General Practice level and grouped at CCG level for as long as there is a business requirement, as agreed with Information Governance. DMS will only deliver to the customer the data grouped at CCG level.

Data is being collected at General Practice level. NHS Digital will receive aggregated counts of patients broken down by General Practice. Data is published at CCG level.

Small numbers are not suppressed, but as the data is only released at CCG level and NHS Digital does not publish which practices participated, it is not possible to disaggregate the CCG totals⁶.

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 detailed specification may be found in [Appendix A](#) of this document.

Manner of the collection

General Practice action to participate in the **LDD** collection via the Calculating Quality Reporting Service (**CQRS**) will vary according to General Practice existing participation arrangements:

1. General Practices currently not participating will be sent an invitation to participate via **CQRS**. This invitation must be accepted as there is a Direction in place for this data collection and it is a legal requirement for General Practices to provide this data under section 259(1)(a). General Practices, whose system suppliers are in scope of this

⁶ A proposal went to the Disclosure Control Panel for the first extract at CCG level. This detailed how the number of small number cells (0 – 5) was 0.07% of the total dataset and the small numbers were always situated within a population of at least 75,000 and are therefore not susceptible to either identification or self-identification of individuals.

collection, are therefore mandated to comply with this invitation and approve the collection.

2. General Practices currently participating do not need to take any further action to remain participating in the data collection.
3. General Practices who want to review their participation status should do so via the participation management tab in **CQRS**.

The required data will be collected from General Practices' clinical IT systems via GPES. The [NHS Digital GP Collections webpage](#)⁷ provides further information on this service.

Once collected, the data will be stored in the NHS Digital secure Data Access Environment (**DAE**) used by NHS Digital.

Period of the collection

This is an existing established data collection via GPES. NHS Digital has been collecting LDD since April 2016. NHSE & NHSI require the annual data extract to continue.

In financial year 2020-21 GPES would usually collect data for financial year 2019-20. However, due to the changes in indicators GPES will collect data for 2015-16 / 2016-17 / 2017-18 / 2018-19 / 2019-20. This is because the publication uses a time series and NHS Digital needs to provide the comparative data to NHSE & NHSI.

This **Notice** advises data will be collected until 30 September 2023.

The [GP live collections timetable](#) 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

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 GPSS 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.

Data quality will be checked against the standard six data quality characteristics, which are: coverage, completeness, validity, default, integrity, and timeliness, as per the requirements of the customer.

Many of the SNOMED CT codes used to specify the data items listed are also used in the Quality and Outcomes and Framework (QOF) and other payment extractions and therefore the data quality of these codes is expected to be high. For other SNOMED CT codes that are not used in payment extractions, the data quality may not be as high.

⁷ <https://digital.nhs.uk/services/general-practice-gp-collections>

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(2)(a) and 265(3) of the 2012 Act, NHS Digital has an assessment process to validate and challenge the level of burden incurred through introducing new information standards, collections and extractions.

This process is carried out by the Data Standards Assurance Service (DSAS) which assures burden assessment evidence as part of the overarching DCB approval process. The DCB, acting under authority of the Secretary of State, oversees the assurance, approval and publication of information standards and data collections 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 extracted by the GPSS. 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	£18.5k	Based upon circa 4,200 General Practices covering three of the four principle system suppliers. 4 minutes per General Practice manager.
Other costs of the data collection	nil	
Total costs	£18.5k	Overall, total burden of GPES collection.

Appendix A: Specification

The data that will be included in the Learning Disabilities Data extract version 3.0, or the latest amended version as agreed by NHS England and NHS Improvement, may be found on the Business Rules page on NHS Digital's website:

<https://digital.nhs.uk/data-and-information/data-collections-and-data-sets/data-collections/quality-and-outcomes-framework-qof#other-extracts>

For further information

www.digital.nhs.uk

0300 303 5678

enquiries@nhsdigital.nhs.uk

Under the Open Government Licence you are encouraged to use and re-use the publicly accessible information in this notice free of charge. Re-use includes copying, issuing copies to the public, publishing, broadcasting and translating into other languages and its subsequent use in commercial or non-commercial enterprise.