

Briefing Paper: Health and Care of People with Learning Disabilities and new LDA ADHD Data Set

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Contents

Introduction	3
Background	3
New LDA ADHD Data Set	4
Content	4
Timescales	5
Appendix A	6

Introduction

This briefing paper provides information on the planned replacement of the data source for the annual publication of the [Health and Care of People with Learning Disabilities \(HCPLD\)](#). NHS England is developing a new patient level data set (the LD ADHD Data Set) which will address some of the limitations of the current data source.

Users of the HCPLD are invited to consider the proposal and provide feedback to inform future data collection and reporting.

Background

NHSE is planning to use the General Practice Extraction Service (GPES) for a new *patient level* data set on people with a learning disability, autistic people and those with ADHD. These three groups of patients face significant health inequalities, high rates of avoidable mortality and poor access to tailored services. The ability to identify these three patient groups in health and care data sets tends to be poor.

The data source for the HCPLD is also a GPES extract and although it is a rich source for primary care data it has some serious limitations:

- It is *aggregate* level, lacking granularity for analysis, e.g. by ethnicity, deprivation, age, and gender.
- It cannot link to other health datasets.
- It only covers around 55% of registered patients due to the high cost of including a key system supplier.
- Adding new data is costly and limited.

Coverage of the HCPLD is a particular issue as whilst some ICBs have registered patient coverage of 95% or more, for others, less than 10% of their registered population is included in the dataset.

New LDA ADHD Data Set

The new LDA ADHD Data Set will include all patients registered with a GP practice in England who are recorded as:

- having a learning disability
- autistic
- having ADHD

The proposed LDA ADHD Data Set would replace the annual extract for the HCPLD and address the current limitations:

- Coverage of the GP registered population in the new data set is expected to be high across the country at 95% or more.
- The new data set could be linked to other health data sets providing access to a much wider set of health data for people with a learning disability, autistic people and those with ADHD
- It will be patient level so the potential for analysis is not restricted in the same way as it is for aggregate data. It enables more in-depth analysis of the data and greater insight. And it therefore represents significant added value.
- The cost of extracting patient level data is lower, so it is possible to include more data in the data set.

Unlike the HCPLD, it has not been possible to include a comparator group of those without a learning disability and/or who are not autistic and/or do not have ADHD in the new LDA ADHD Data Set. NHS England plans to develop comparators in due course through data linkage and other data sources (e.g. QOF, the National Diabetes Audit and OpenSafely). Specifications for the new data set are being developed to be consistent with the HCPLD and existing QOF indicators where possible.

Content

The current content of the aggregate GPES extract that supports the HCPLD has been reviewed and most of the data currently included in that extract will be included in the new LDA ADHD Data Set, but the new data set would additionally cover:

- A more comprehensive list of the long-term conditions identified as the primary causes of premature mortality and morbidity for people with a learning disability and autistic people; and
- Data to support NHSE’s autism and ADHD programmes to understand and address the primary health issues and inequalities for these groups.
- Additional data relating to annual health checks for people with a learning disability.

A full list of data items to be included in the data set is set out in Appendix A. Note that some of the data listed in the specification will be obtained through linkage to other health data sets.

Timescales

The new LDA ADHD Data Set would be an annual extract and the first one is planned for December 2026.

Due to resource constraints in NHS England, it is not possible to resource both the HCPLD publication and the new LDA ADHD data set, so there will be no HCPLD publication in December 2026. Instead, there is a new data set and report planned for Summer 2027. The new report is expected to develop iteratively as it is unlikely that we will be able to report on all data from the data set in the first year.

Appendix A

The table provides a description of the proposed groupings of data items to be included in the data set for each of the patients in the cohort. These will be subject to clinical review.

<i>Description</i>
ID1: Patient's date of birth
ID2: Patient's NHS Number
ID3: Post code of patient's current address only
ID4: The national practice code for the GP practice
ID5: Patient's sex
NEW: Patient's Active status at reporting period end date
ID6: The date and code of the most recent ethnicity recorded up to and including the reporting period end date
ID7: The date and code of the earliest identification of learning disability without a subsequent learning disability exclusion code recorded up to and including the reporting period end date
ID8: The date and code of the earliest Down Syndrome diagnosis recorded up to and including the reporting period end date
ID9: The date and code of the earliest recording of autism up to and including the reporting period end date
ID10: The date and code of the most recent code indicating the patient has deceased recorded up to and including the reporting period end date.
ID11: All dates, codes and values of BMI (or Down syndrome BMI centile classification) recorded within the 12 months up to and including the reporting period end date.
ID12: The date, code and value of the most recent waist circumference with an associated value recorded within the 12 months up to and including the reporting period end date.
ID13: The date, code and value of the most recent height recording with an associated value recorded within the 12 months up to and including the reporting period end date
ID14: The date, code and values of the most recent blood pressure test recorded up to and including the reporting period end date
ID15: The date and code of the most recent hypertension diagnosis without a subsequent hypertension resolved code recorded up to and including the reporting period end date
ID16: The date, code and prescription values of the most recent antihypertensive medications prescribed within the 6 months up to and including the reporting period end date. Returned only for patients with unresolved hypertension (i.e. patients whose latest hypertension diagnosis is not superseded by a hypertension resolved code recorded up to and including the reporting period end date)
ID17: The date, code and value of the most recent QRISK score with an associated value recorded within the 12 months up to and including the reporting period end date.

<i>Description</i>
ID18: The most recent date and code indicating the patient is unsuitable or has chosen not to have a cardiovascular disease (CVD) risk assessment recorded up to and including the reporting period end date.
ID19: The date, code and value of the most recent low-density lipoprotein (LDL) cholesterol test with an associated value recorded in the 12 months up to and including the reporting period end date.
ID19b: The date, code and value of the most recent non-high density lipoprotein (Non-HDL) cholesterol test with an associated value recorded in the 12 months up to and including the reporting period end date
ID20: The date, code and prescription value of the most recent lipid lowering therapy medication (including statins, ezetimibe, PCSK9 inhibitors, inclisiran and bempedoic acid) prescribed within the 6 months up to and including the reporting period end date
ID21: The date, code and value of the most recent HbA1c reading recorded up to and including the reporting period end date
ID22: The date and code of the most recent medication review recorded up to and including the reporting period end date
ID23: The date and code of the most recent cervical screening recorded up to and including the reporting period end date.
ID23b: The date and code of the most recent complete removal of cervix recorded up to and including the reporting period end date
ID25: The date and code of the most recent breast cancer screening recorded up to and including the reporting period end date.
ID28: The date and code of the most recent bowel cancer screening where the sample was adequate recorded in the 24 months up to and including the reporting period end date.
ID29b: The date and code of the most recent Abdominal Aortic Aneurysm (AAA) screening completed recorded up to and including the reporting period end date
ID30: The date and code of the most recent invited for influenza vaccine recorded on or after the 1 September 2025 and up to and including the 31 March
ID31: The date and code of the most recent influenza vaccine recorded on or after the 1 September 2025 and up to and including the 31 March 2026.
ID32: The date and code of the most recent pneumococcal vaccine received recorded up to and including the reporting period end date.
ID34: The date and code of the most recent dementia diagnosis recorded up to and including the reporting period end date
ID35: The date and code of the most recent chronic constipation diagnosis recorded up to and including the reporting period end date
ID36b: The date, code and prescription values of the most recent constipation medication prescription recorded in the 12 months up to and including reporting period end date.
ID37: The date and code of the most recent asthma diagnosis without a subsequent asthma resolved code recorded up to and including the reporting period end date
ID37b: The date, code and prescription value of the most recent Asthma related drug treatment prescription recorded in the 12 months up to and including the reporting period end date.
ID38: The date and code of the most recent annual asthma review recorded up to and including the reporting period end date

<i>Description</i>
ID39: The date and code of the latest first or new cancer diagnosis episode, excluding non-melanotic skin cancer, recorded up to and including the reporting period end date.
ID40: The date and code of the earliest coronary heart disease diagnosis recorded up to and including the reporting period end date
ID42: The date and code of the most recent epilepsy diagnosis without a subsequent epilepsy resolved code recorded up to and including the reporting period end date.
ID45: The date, and code of the most recent Obstructive Sleep Apnea (OSA) recorded up to and including the reporting period end date
ID46: The date, and code of the most recent Circadian rhythm disorder recorded up to and including the reporting period end date
ID47: The date, and code of the most recent Sleep movement disorder recorded up to and including the reporting period end date
ID48: The date, and code of the most recent Parasomnias recorded up to and including the reporting period end date
ID44: The date, and code of the most recent Insomnia recorded up to and including the reporting period end date
ID49a: The date and code of the most recent psychosis diagnosis recorded up to and including the reporting period
ID49b: The date and code of the most recent bipolar affective disease diagnosis recorded up to and including the reporting period
ID49c: The date and code of the most recent schizophrenia diagnosis recorded up to and including the reporting period
ID49d: The date and code of the most recent serious mental illness diagnosis (excluding psychosis, bipolar and schizophrenia) recorded up to and including the reporting period
ID49e: The date and code of the most recent psychosis in-remission code recorded up to and including the reporting period end date
ID49f: The date and code of the most recent bipolar affective disease in-remission code recorded up to and including the reporting period end date
ID49g: The date and code of the most recent schizophrenia in-remission code recorded up to and including the reporting period end date
ID50: The date and code of the most recent Hypothyroidism diagnosis recorded up to and including the reporting period end date
ID52a: The date and code of the earliest heart failure diagnosis recorded up to and including the reporting period end date
ID52b: The date and code of the earliest abdominal aortic aneurysm diagnosis recorded up to and including the reporting period end date.
ID52c: The date and code of the earliest peripheral arterial disease recorded up to and including the reporting period end date
ID53: The date and code of the earliest stroke or transient ischaemic attack recorded up to and including the reporting period end date.
ID56: The date and code of the most recent non-diabetic hyperglycaemia diagnosis recorded up to and including the reporting period end date

<i>Description</i>
ID57: The date and code of the most recent diabetes diagnosis without a subsequent diabetes resolved code recorded up to and including the reporting period end date
ID57b: The date and code of the most recent diabetes in-remission code without a subsequent diabetes diagnosis code recorded up to and including the reporting period end date. If the diagnosis and in-remission code are on the same day do not return the in-remission code
ID59: The date and code of the earliest chronic obstructive pulmonary disease (COPD) diagnosis recorded up to and including the reporting period end date
ID60: The date and code of the most recent osteoporosis diagnosis recorded up to and including the reporting period end date
ID61: The date and code of the most recent chronic kidney disease stage 3-5 without a subsequent chronic kidney disease stage 1-2 or chronic kidney disease resolved code recorded up to and including the reporting period end date
ID63b: The date and code of the most recent record indicating the patient has received an NHS health check recorded up to and including the reporting period end date
ID64a: The date and code and value of the most recent fast alcohol screening test or alcohol use disorder identification test recorded up to and including the reporting period end date
ID64b: The date and code and value of excessive alcohol consumption recorded up to and including the reporting period end date
ID64c: The date and code and value of the most recent alcohol consumption or alcohol usage code recorded up to and including the reporting period end date
ID65: The date and code of the most recent smoking habit recorded within the 12 months up to and including the reporting period end date.
ID66: The date and code of the most recent Illicit substance abuse recorded within the 12 months up to and including the reporting period end date.
ID67: The date and code of the earliest recording of ADHD up to and including the reporting period end date
ID68: The date and code of the most recent depression diagnosis without a subsequent depression resolved code recorded up to and including the reporting period end date
ID69: The date and code of the most recent anxiety diagnosis without a subsequent anxiety resolved code recorded up to and including the reporting period end date
ID70: The date and code of the most recent learning disability health check recorded up to and including the reporting period end date
ID71: The date and code of the most recent learning disability health action plan recorded up to and including the reporting period end date
ID72: The date, code and prescription value of the most recent antipsychotic prescription recorded in the 12 months up to and including the reporting period end date
ID72b: The date, code and prescription value of the most recent lithium prescription without a subsequent lithium stopped code, recorded in the 6 months up to and including the reporting period end date
ID72c: The date and code of the most recent palliative care code without a subsequent palliative care no longer indicated code, recorded on or after the 1 April 2008 and up to and including the reporting period end date
ID73: The date, code and prescription value of the most recent benzodiazepine prescription recorded in the 12 months up to and including the reporting period end date

<i>Description</i>
ID74: The date, code and prescription value of the most recent epilepsy prescription recorded in the 12 months up to and including the reporting period end date
ID75: The date, code and prescription value of the most recent melatonin prescription recorded in the 12 months up to and including the reporting period end
ID76: The date and code of the most recent Crohn's disease diagnosis recorded up to and including the reporting period end date
ID77: The date and code of the most recent gastroesophageal reflux disease (GORD) diagnosis recorded up to and including the reporting period end date
ID78: The date and code of the most recent appendicitis diagnosis recorded up to and including the reporting period end date
ID79: The date and code of the most recent ulcerative colitis (IBD) diagnosis recorded up to and including the reporting period end date
ID80: The date and code of the most recent peptic ulcer disease diagnosis recorded up to and including the reporting period end date
ID81: The date and code of the most recent eating disorder recorded up to and including the reporting period end date
ID82: The date, code and prescription value of the most recent antidepressants prescription recorded in the 12 months up to and including the reporting period end date
ID83: The date, code and prescription value of the most recent ADHD prescription recorded in the 12 months up to and including the reporting period end date
ID84: The date and code of the most recent has a carer code recorded up to and including the reporting period end date
ID87: All dates and codes of suicide attempts in the 3 years up to and including the reporting period end date
ID86: All dates and codes of known self-harm in the 2 years up to and including the reporting period end date
ID89: The date and code of the most recent PCOS and polycystic ovaries diagnosis recorded in the 24 months up to and including the reporting period end date
ID90: All dates and code of menstruation related issues recorded within the 24 months up to and including the reporting period end date
ID91: The date and code of the most recent Ehlers danlos syndrome diagnosis recorded up to and including the reporting period end date
ID92: The date and code of the most recent referral to gender services recorded up to and including the reporting period end date
ID94: The date, code and value of most recent urine ACR recorded up to and including the reporting period end date
ID96: The date and code of the most recent diabetic foot check recorded up to and including the reporting period end date