

# Learning Disabilities Statistics - Annual Overview

## England 2015-2016, Experimental Statistics

This is the first annual report from the HSCIC on people with learning disabilities and/or autistic spectrum disorder. It includes commentary on the currently available sources of learning disability statistics produced by HSCIC as well as fresh analysis of the Assuring Transformation collection.

### Between March 2015 and February 2016



**1,800**

Admissions/transfers  
to hospital



**1,970**

Discharges/transfers  
from hospital



**2,650**

People receiving inpatient  
care on 29 February 2016

**895**



People have been receiving  
continuous inpatient care for  
over 5 years

**280**



Admissions/transfers in the  
year were for those under 18  
years old

All figures shown above are taken from the Assuring Transformation collection and relate to patients receiving care in specialist facilities. All patients have or are thought to have a learning disability and/or autistic spectrum disorder. The Assuring Transformation collection was commissioned as part of 63 initiatives identified within 'Transforming Care: A national response to Winterbourne View Hospital' ('Transforming Care') in response to the abuse at Winterbourne View Hospital.

Read the full report to find out more: [www.hscic.gov.uk/pubs/lids1516](http://www.hscic.gov.uk/pubs/lids1516)

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## Executive summary

This release presents experimental statistics from the Assuring Transformation (AT)<sup>1</sup> collection and considers data from the Learning Disability Census (LDC)<sup>2</sup>; Hospital Episodes Statistics (HES)<sup>3</sup>; Quality Outcomes Framework (QOF)<sup>4</sup>; Mental Health and Learning Disabilities Data Set (MHLDDS) and Mental Health Services Data Set (MHSDS)<sup>5</sup> all published by the Health and Social Care Information Centre (HSCIC).

The publication comprises:

- This report which presents key measures at England level;
- Excel reference data tables showing all annual analysis at England, CCG and provider level;
- CSV file showing all annual analyses at England, CCG and provider level;
- A metadata file to accompany the CSV file, which provides contextual information for each measure;
- Derivations and constructions file detailing how measures were calculated.

It is published on the HSCIC website here:

<http://www.hscic.gov.uk/pubs/lids1516>

The majority of this publication considers data from the Assuring Transformation collection, analysing data from a different perspective to the regular monthly and quarterly releases. Data covers the year ending 29 February 2016. For analysis, a snapshot<sup>6</sup> of the data was taken as at 31 March 2016.

## Scope of the Assuring Transformation collection

The collection comprises inpatients with 'a bed' normally designated for the treatment or care of people with a learning disability or those with 'a bed' designated for mental illness treatment or care who have been diagnosed or are understood to have a learning disability and/or autistic spectrum disorder.

Data is collected from Clinical Commissioning Groups (CCGs) and Commissioning Hubs (Hubs)<sup>7</sup>. In some cases, Commissioning Support Units (CSUs) submit data on behalf of one or more CCGs.

Data are provided by English commissioners and healthcare is typically provided in England, although care commissioned in England and provided elsewhere in the UK is included. There is a slight difference in scope between this collection and the Learning Disability Census<sup>8</sup> since the

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<sup>1</sup> <http://www.hscic.gov.uk/assuringtransformation>

<sup>2</sup> <http://www.hscic.gov.uk/lidcensus>

<sup>3</sup> <http://www.hscic.gov.uk/hes>

<sup>4</sup> <http://www.hscic.gov.uk/qof>

<sup>5</sup> <http://www.hscic.gov.uk/mhstds>

<sup>6</sup> For more information on the time frame used, see Annex 1

<sup>7</sup> For more information on the different roles of CCGs and Hub see: <http://www.england.nhs.uk/wp-content/uploads/2014/01/pss-manual.pdf> Note that Hubs have replaced Specialised Commissioning Teams (SCTs) which are referenced in this link.

<sup>8</sup> More information on the Learning Disability Census can be found here: <http://www.hscic.gov.uk/lidcensus>

Census comprises data from providers based only in England, and includes care provided in England but commissioned from other UK countries<sup>9</sup>.

## Data presentation

In order to minimise the disclosure risk associated with small numbers, all Assuring Transformation figures presented within this report, reference data tables and CSV have had the following suppression rules applied:

- Values of 0-4 have been replaced by \*;
- Values have been rounded to the nearest 5;
- Percentage calculations were based on unrounded figures and have been rounded to a whole number.

All figures are calculated from the raw data, suppressed where needed and then rounded. This may mean that some totals presented in tables here do not match the sum of the subtotals within the same table.

Figures not sourced from Assuring Transformation and presented within this report and within the reference data tables may be under the same suppression rules, alternate rules will be identified accordingly.

This information is released under 'experimental' status. This is a concept used for statistics in certain defined circumstances, largely to develop (with user input) new data sets which already have considerable immediate value to users, but are not fully developed and do not yet meet the quality standards of National Statistics. It is important that users understand that cautions apply to the interpretation of this data.

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<sup>9</sup> This report also considers the difference in learning disability data from other collections. However both Assuring Transformation and the Learning Disability Census were commissioned following the Winterbourne View scandal so focus on the specific cohort of people receiving inpatient care.

## Key Facts

Between 1 March 2015 and 29 February 2016 there were<sup>10</sup>:

- 2,650 patients receiving inpatient care at the end of February 2016 compared to 2,820 at the end of February 2015;
- 1,800 admissions/transfers to inpatient care;
- 1,970 discharges/transfers from inpatient care;
- 895 people have been receiving continuous inpatient care for over 5 years.

Aged under 18

- Of admissions/transfers in the year, 280 were under 18 years old at the time of admission;
- Of discharges/transfers in the year, 235 were under 18 years old at the time of discharge;
- Of those who were under 18 years old on admission 10<sup>11</sup> patients were recorded as receiving continuous inpatient care for over 5 years.

MHSDS<sup>12</sup> started collecting data from January 2016 onwards, initial figures<sup>13</sup> indicate:

- 57,608 people were in contact with Learning Disability Services<sup>14</sup> in January 2016 as per the new MHSDS collection<sup>15</sup>

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<sup>10</sup> Data are retrospectively updated to include late data submissions from commissioners. The final figures are true as of 31 March 2016.

<sup>11</sup> Approximately 10 patients. Data is taken from Reference Data Table 11 where suppressed data shows 5 people in care over 5 years and 5 people in care over 10

<sup>12</sup> MHSDS stands for Mental Health Services Data Set [www.hscic.gov.uk/mhsds](http://www.hscic.gov.uk/mhsds)

<sup>13</sup> <http://www.hscic.gov.uk/pubs/mhsjan16prov>

<sup>14</sup> This includes secondary mental health, learning disabilities or autism spectrum disorder services in England and not inpatient services in this count.

<sup>15</sup> 53,920 people were in contact with Learning Disability services in November 2015 as per the final release of Mental Health and Learning Disability Services Data Set <http://www.hscic.gov.uk/catalogue/PUB20050>

## Introduction

This publication collates information from a range of statistics on Learning Disabilities into a single resource. The aim is to address the difference in data collections. The HSCIC has collected Assuring Transformation (AT) data for over a year, and this report will present detailed analyses over this time period.

All data is presented in Excel Reference Data Tables and a CSV file. Readers are encouraged to view the data in these outputs along with the data quality notes in this report. This report highlights the main areas of analysis undertaken and presented in the aforementioned releases.

The report covers the following areas:

- Timeline of data available on people with learning disabilities and/or autism;
- Overview of the data collections containing data on people with a learning disability and/or autism;
- Results of linking Hospital Episodes Statistics to Assuring Transformation, commissioned by NHS England.

Assuring Transformation Analysis:

- All inpatients by different cuts of the data and by key measures for demographics, reason for inpatient care, length of stay and distance from home amongst others;
- Under 18s focused analysis;
- Data quality measures.

## Data on inpatients with Learning Disabilities and/or autism, a timeline of data availability

The BBC One Panorama programme “Undercover Care: The Abuse Exposed”<sup>16</sup> alerted viewers in May 2011 to the mistreatment and assault of adults with learning disabilities and autistic spectrum disorder within Winterbourne View Hospital. There followed a Serious Case Review conducted by South Gloucestershire Adult Safeguarding Board<sup>17</sup> and a series of publications by the Department of Health.<sup>18</sup>

The Department of Health developed a change programme designed to address the transformation of care and support for people who have learning disabilities or autistic spectrum disorder and may also have mental health needs or behaviours experienced as challenging. Both Assuring Transformation and the Learning Disability Census were commissioned as part of 63 initiatives identified within ‘Transforming Care: A national response to Winterbourne View Hospital’ (‘Transforming Care’)<sup>19</sup> in response to the abuse at Winterbourne View Hospital.

The signatories to the Department of Health ‘Winterbourne View Review Concordat: Programme of Action’<sup>20</sup> (‘Concordat’) committed to a change programme in order to transform health and care services and in so doing improve the quality of the care offered to children, young people and adults with learning disabilities, autistic spectrum disorder and/or behaviour that challenges, to ensure better care outcomes for them.

Prior to these collections the most recent data on inpatients with learning disabilities and/or autism were collected as part of the Care Quality Commissions 2010 Count me in Census<sup>21</sup>.

Today the HSCIC collects and publishes a range of statistics on people with learning disabilities and/or autism receiving inpatient care in England as well as people in touch with community services and registered with their GP. This report brings all these together, considers the differences and looks to possibilities for the future.

## Comparison of the available data sources

Reference data table 1 shows the current available sources of data for people with learning disabilities and/or autism. Four collections are able to measure similar metrics (Assuring Transformation, Hospital Episodes Statistics, the Learning Disability Census and Mental Health Services Data Set). However numbers often differ. This section puts forward various possibilities for this using the most up-to-date evidence we have currently.

### Assuring Transformation and Learning Disability Census

Both collections cover a similar cohort of people. The Learning Disability Census is a provider based collection of people receiving inpatient care in England. While Assuring Transformation is a

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<sup>16</sup> <http://www.bbc.co.uk/programmes/b0111pwt6> Note: the program is no longer available on BBC IPlayer. The programme is available in on You Tube (2 x 15 min clips, Part 1 - <https://www.youtube.com/watch?v=Qy3qg32hKFc> & Part 2 - [https://www.youtube.com/watch?v=Uh-vJXX53\\_Y](https://www.youtube.com/watch?v=Uh-vJXX53_Y))

<sup>17</sup> <http://sites.southglos.gov.uk/safeguarding/adults/i-am-a-carerrelative/winterbourne-view/>

<sup>18</sup> <https://www.gov.uk/government/publications/winterbourne-view-hospital-department-of-health-review-and-response>

<sup>19</sup> <https://www.gov.uk/government/publications/winterbourne-view-hospital-department-of-health-review-and-response>

<sup>20</sup> [https://www.gov.uk/government/uploads/system/uploads/attachment\\_data/file/213217/Concordat.pdf](https://www.gov.uk/government/uploads/system/uploads/attachment_data/file/213217/Concordat.pdf)

<sup>21</sup> [http://socialwelfare.bl.uk/subject-areas/services-client-groups/adults-mental-health/carequalitycommission/155293count me in 2010 final tagged.pdf](http://socialwelfare.bl.uk/subject-areas/services-client-groups/adults-mental-health/carequalitycommission/155293count%20me%20in%202010%20final%20tagged.pdf)

commissioner based collection of people whose care is commissioned in England, but care may be provided elsewhere.

The 2015 Learning Disability Census<sup>22</sup> linked the two data sources together and investigated the differences. In part this is due to the variation due one being a commissioner and the other a provider collection; however this does not explain all the differences in the data. Patient numbers at provider and commissioner level were published as part of this work. Following this linkage, data was shared with NHS England so that commissioners could be contacted and asked to investigate if patients needed to be added into the Assuring Transformation collection. This will have had an impact on the Assuring Transformation patient counts for previous months since commissioners retrospectively adjusted their patient records. Providers were contacted, and although the Learning Disability Census will not run again, the data will be taken from the MHSDS collection so providers were asked to ensure this collection is robust and complete.

### Assuring Transformation and Hospital Episodes Statistics

NHS England commissioned HSCIC to link the Assuring Transformation collection to Hospital Episodes Statistics (HES)<sup>23</sup>. The number of inpatient episodes recorded in HES for people with learning disabilities and autism is higher than the numbers seen in Assuring Transformation. A bespoke analysis considered patients in HES by the criteria set out in annex 2, the patients identified in HES were then linked to the Assuring Transformation collection on NHS number and hospital admission date.

This analysis found that for March 2015, HES reported there were 1,015 admissions to hospital for treatment of mental health and/or behavioural issues related to learning disability and autism compared to 150 in Assuring Transformation<sup>24</sup>. Of the 1,015 admissions recorded in HES, 35 were also recorded in Assuring Transformation. Within the HES data, 690 admission were recorded as being for respite care only, none of these admissions were reported to HSCIC via the Assuring Transformation data collection.

Reference data table 15 shows the comparison.

### Learning Disability Census and MHLDDS<sup>25</sup>

The Mental Health and Learning Disabilities Data Set (MHLDDS) ran from September 2014 to November 2015<sup>26</sup> and collected data on adults in contact with mental health and learning disability services in the community and receiving specialist care in hospital. This was a secondary uses data set and re-used clinical and operational data submitted to HSCIC by service providers for purposes other than direct patient care. Both NHS and independent providers who provided care for NHS funded patients in England were mandated to provide a monthly data return.

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<sup>22</sup> <http://www.hscic.gov.uk/article/6468/Reports-from-the-Learning-Disability-Census-collections>

<sup>23</sup> Annex 2 explains the rationale and linkage

<sup>24</sup> Assuring Transformation data for March 2015 was taken from a snapshot at end of December 2015. The inpatient count for March 2015 will have altered since that data cut in December due to commissioners informing HSCIC of patients who should have been added to the CAP system prior to March 2015.

<sup>25</sup> Suppression rules for MHLDDS can be found within the final report for the MHLDDS publication:

<http://www.hscic.gov.uk/catalogue/PUB20050/mhlds-monthly-exec-Nov-2015.pdf>

<sup>26</sup> Prior to September 2014 this was the Mental Health Minimum Dataset and did not formally collect data on people with learning disabilities <http://www.hscic.gov.uk/mhldsreports>

For September 2015, MHLDDS reported<sup>27</sup> that 55,615 people were in touch with NHS funded specialist secondary learning disability services and 1,474 people were in wards designated for learning disabilities. The 2015 Learning Disability Census reported 3,000 people in scope of the collection<sup>28</sup>, of which 2,255 were in a ward whose service type was identified as learning disability<sup>29</sup>.

Table 1 shows an initial investigation into the differences between the two collections by doing simple counts. MHLDDS was last published for November 2015 final data and December provisional.

**Table 1 number of people receiving inpatient care in ward for learning disabilities, as of MHLDDS and LDC September 2015, and by how many providers supplied the data.**

Measure	Data source	Total	Independent sector providers	NHS providers
Number of people receiving inpatient care in a ward for learning disabilities	MHLDDS	1,474	120	1,354
	LDC	2,255	1,030	1,220
Number of providers	MHLDDS	27	2	25
	LDC	60	18	42

Source: Learning Disability Census 2015, Mental Health and Learning Disabilities Data set September 2015 – final

### MHSDS and future work

From January 2016 MHLDDS was replaced by the Mental Health Services Dataset (MHSDS)<sup>30</sup> and expanded in scope to include children and young people's services. The MHSDS is used to derive statistics covering three areas: Adult Mental Health, Child and Young People's Mental Health Services and Learning Disability Services.

Data is published monthly and currently uses the type of service a person is receiving or the type of ward the person is an inpatient in to distinguish between the three areas. Depending on what is being measured a person could be in touch with more than one service.

HSCIC are currently developing a method within the MHSDS dataset to be able to identify patients in scope of Learning Disability Census and Assuring Transformation. The method will also be able to identify people with learning disabilities and/or autism in touch with community services. It is expected that MHSDS and Assuring Transformation will run in parallel for some time to ensure the quality of the MHSDS learning disability and /or autism inpatient count. The introduction of community services and linking these together will create a rich data source.

### Quality and outcomes framework (QOF)

Quality and Outcomes Framework (QOF) is the annual reward and incentive programme detailing GP practice achievement results. It is a voluntary process for all surgeries in England and was

<sup>27</sup> <http://www.hscic.gov.uk/pubs/mhldssep15>

<sup>28</sup> The scope of the Census was wider than just people in a bed identified as a learning disability 'bed' and included people with a learning disability or autism in a mental health bed. For the full scope see:

<http://www.hscic.gov.uk/ldcensus>

<sup>29</sup> See Reference data table 3 in the 2015 initial results <http://www.hscic.gov.uk/pubs/ldcensus15>

<sup>30</sup> <http://www.hscic.gov.uk/mhsds>

introduced as part of the GP contract in 2004. As part of the collection, there is a measure on the prevalence of patients recorded as having a learning disability in England. Data for 2014/15 shows that 0.4% of patients are registered with their GP as having a learning disability, this equates to approximately 217,266,<sup>31</sup> people in England. There are currently no figures collected on prevalence of autism recorded at GP practices.

## Assuring Transformation – Annual data March 2015 - February 2016

### All patients analysis

Reference data tables 2 – 7 and 12,13 and 14 show analysis of the Assuring Transformation collection. Using a years' worth of data allows for are some additional measures which are not possible in the regular monthly publications due to low numbers.

The reference data tables provide information on:

- All inpatients at the end of February 2016
- All inpatients who have remained in the Assuring Transformation collection between March 2015 and February 2016 and never left hospital
- All admissions between March 2015 and February 2016
- All transfers/discharges between March 2015 and February 2016
- All inpatients with a length of stay of 5 years or more as part of continuous inpatient care
- All inpatients with a length of stay of 5 years or more in the same hospital

Data quality measures:

- Number of times a planned transfer date is altered
- How recently a patient record has been updated

Figure 1 demonstrates the annual flow of patients recorded by the Assuring Transformation collection<sup>32</sup>. In each monthly publication the HSCIC retrospectively update previously published month end count figures to include late submissions by commissioners. This is still having an impact on all monthly figures. With this in mind, counts for the year March 2015 to February 2016 are likely to change over time as new episodes of care are reported to the HSCIC, we would traditionally expect the count of the number of inpatients at the end of February to increase.

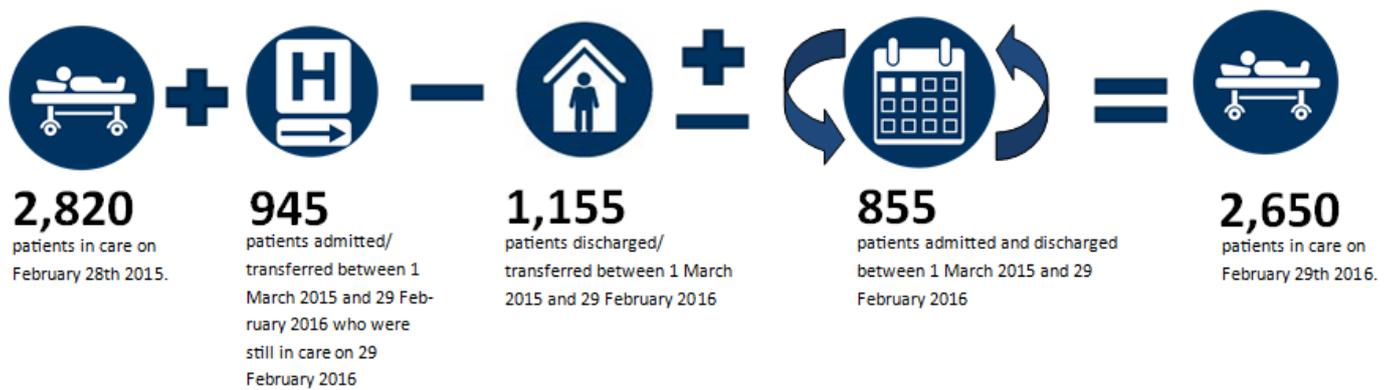
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<sup>31</sup> 54,316,618 people in England in 2014 as per ONS population statistics

<https://www.ons.gov.uk/peoplepopulationandcommunity/populationandmigration/populationestimates/adhocs/004359englandpopulationestimates1971to2014>

<sup>32</sup> The monthly reference data tables show data from March 2015 since NHS England use March 2015 as a baseline for monitoring the reduction in inpatient numbers. However, responsibility for collecting data for the Assuring Transformation collection moved to HSCIC from February 2015 onwards.

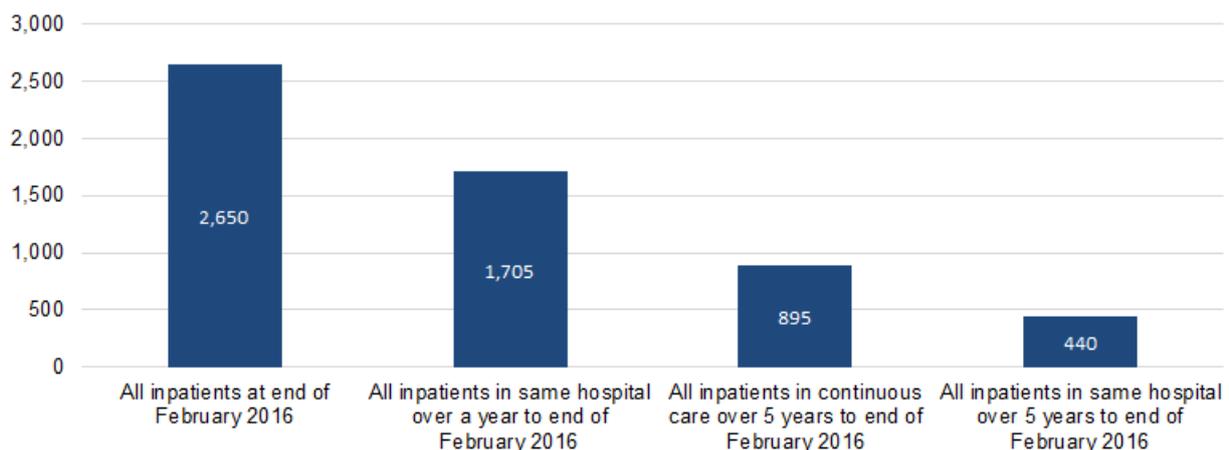
**Figure 1: flow of patients in the Assuring Transformation collection over the past year**



Source: Learning Disability Statistics – Annual overview: Table 2

Figure 2 shows the inpatient count at the end of February 2016, subsequent bars than display patients still receiving care at the end of February 2016 by length of stay.

**Figure 2: Overall patient counts at the end of February 2016, and count of patients receiving inpatient care for over a year or more.**



Source: Learning Disability Statistics – Annual overview: Table 3

## Under 18s analysis

Reference data tables 8-11 show analysis for those under 18. Depending on the period being analysed, the age is defined at admission, discharge or 29 February 2016. This is stated in the measure title. Using a year’s worth of Assuring Transformation data provides a richer source of data for those under 18, additional analyses undertaken are:

- Age under 18 at admission by length of stay and total length of stay (to discharge or February 2016 if still in care)
- All admissions in the year
- All discharges in the year

Annex 1 provides more information on how age was defined and how this is different for certain measures.

## Annex

### Annex 1 – Definition of measures for Assuring Transformation collection

Data were collected via the Clinical Audit Platform (CAP). Commissioners are expected to keep information up to date on an ongoing basis, to facilitate analysis, a snapshot of the data is taken at the end of the month. For this report the snapshot was taken on 31-3-2016 and data in the period 1-3-2015 to 29-2-2016 make up the majority of this analysis.

The following definitions and constructions were used in the data analyses. The tables below show plain English version of measures. A detailed technical output can be viewed within the constructions and derivations file produced as part of this release.

**Table 2: Defining the cohorts of inpatients analysed.**

Cohort	Time frame	Used in reference data table
All inpatients at end of Feb 2016	All patients still in hospital on 29-2-2016	3,4,5,12,13
All inpatients in same hospital Mar 2015 - Feb 2016	All patients in the same hospital between 1-3-2015 and 29-2-2016	3,4,5,12,13,14
All inpatients in continuous care since Mar 2011	All patients who have not left hospital but may have transferred between one or more hospital and whose first episode of continuous inpatient care started before 1-3-2011	3,4,5,12,13,14
All inpatients in same hospital since Mar 2011	All patients who have not left this hospital and whose inpatient care started before 1-3-2011	3,4,5,12,13,14
All admissions Mar 2015 -Feb 2016	All admissions to hospital where the date of admission falls between 1-3-2015 and 29-2-2016	3,4,5,6
All discharges Mar 2015 - Feb 2016	All discharge/transferred from hospital where the date of discharge/transfer falls between 1-3-2015 and 29-2-2016	3,4,5,7

**Table 3: Defining data quality measures analysed**

Measure	Time frame	Used in reference data table
Record last updated	March 2015 to March 2016. Since the data was taken at 31 March 2016 records could also have been updated during March 2016	14
Time to planned transfer altered	March 2015 to February 2016	14

## Under 18s analysis

Those aged under 18 are identified as under 18 at different points in their time in care depending on the analysis being undertaken. Table 3 sets out the method<sup>33</sup>

**Table 3: Defining the cohorts of inpatients analysed for aged under 18s**

Under 18 cohort	Point in time at which age is defined as under 18	Time frame	Used in reference data table
All inpatients at end of Feb 2016	End of February 2016	Patients still in hospital on 29-2-2016	8,9,10
All inpatients in same hospital Mar 2015 - Feb 2016	Must have been under 18 at the start of the year	Patients in the same hospital between 1-3-2015 and 29-2-2016	8,9,10
All admissions Mar 2015 -Feb 2016	Under 18 at time of admission	Admission to hospital falls between 1-3-2015 and 29-2-2016	8,9,10
All discharges Mar 2015 - Feb 2016	Under 18 at time of discharge	Discharge/transferred from hospital between 1-3-2015 and 29-2-2016	8,9,10
All admissions under 18 years old	Under 18 at the time of admission	Admitted any time before 29-2-2016 and either still in care or discharged after March 2015	11

## Annex 2 – Linking AT to HES

The following definitions were used to identify a cohort of patients with learning disabilities/and or autism in the HES collection. To be included the record had to meet the criteria set out by NHS England below.

### Identifying people in HES<sup>34</sup>

Include any patient meeting any of these criteria for main specialty code or diagnosis:

- Main Specialty Code 700 – any Diagnosis Code (primary or otherwise);
- Any Main Specialty Code 710-727 AND a Diagnosis Code of either F7xx (Learning Disability) or F84x (Autistic Spectrum Disorder) included as a primary or secondary diagnosis.
- Any patient with Treatment Function Code 319 AND a Diagnosis Code of either F7xx (Learning Disability) or F84x (Autistic Spectrum Disorder) included as a primary or secondary diagnosis, who is not included in either of the above groups.

For these patients, include all activity for March 2015:

- All patients admitted in March 2015;
- All patients that were continuously in inpatient beds from the beginning to the end of the month (including those who have transferred from one provider or setting to another);
- All patients discharged from hospital care during the March 2015.

<sup>33</sup> The Assuring Transformation collection transferred to HSCIC from February 2015. Discharges that took place during February may not be fully representative of the data and any data that was received where a transfer took place prior to February 2015

<sup>34</sup> For more information in the codes see HES admitted patient data dictionary <http://www.hscic.gov.uk/hesdatadictionary>

## Identifying people in AT

The AT collection for March 2015 as of December 2015 also identified:

- All patients admitted in March 2015;
- All patients that were continuously in inpatient beds from the beginning to the end of the month (including those who have transferred from one provider or setting to another);
- All patients discharged from hospital care during the March 2015.

## Linking the two together

The two datasets were then linked together on NHS number and date of admission. This was to ensure that patients with multiple admissions linked to the correct episode. Where duplicate episodes (or what appeared to be duplicates by considering NHS number and hospital admission date) were identified the duplicates were removed to leave one record that could be linked.

## Identifying respite care in HES

Patients were identified as receiving respite care if they had either Treatment Function code of 319 or Diagnosis Code of Z755 in HES<sup>35</sup>

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<sup>35</sup> HES code Treatment Function code 319 identifies respite care. Primary diagnosis codes use ICD-10 codes. Z755 identifies holiday relief care.

## Annex 3 - Data quality report: assessment of statistics against quality dimensions and principles

This section provides details and data quality information for the Assuring Transformation data used in this publication<sup>36</sup>. It aims to provide users with an evidence based assessment of the quality of the statistical output by reporting against those of the European Statistical System (ESS) quality and related dimensions and principles<sup>37</sup> appropriate to this output.

In doing so, this meets HSCIC obligation to comply with the UK Statistics Authority (UKSA) Code of Practice for Official Statistics<sup>38</sup>, particularly Principle 4, Practice 2 which states: “Ensure that official statistics are produced to a level of quality that meets users’ needs, and that users are informed about the quality of statistical outputs, including estimates of the main sources of bias and other errors, and other aspects of the European Statistical System definition of quality”.

Due to the experimental status and the provisional nature of some of the data from operational processes, some figures may be revised from publication to publication as issues are uncovered and resolved. The experimental status allows for this to occur if it is determined that a refresh of data is required subsequent to initial release. Where a refresh of data occurs, it will be clearly documented in the publications. Users should always use the figures in the latest publication to ensure they are the most up to date figures available.

### Relevance

*This dimension covers the degree to which the statistical product meets user need in both coverage and content.*

This release comprises this report, Reference data tables, CSV file and metadata file and constructs & derivations. This report brings together information on people the learning disabilities and /or autism from various sources to inform users of data differences. The bulk of the analysis concentrates on the Assuring Transformation collection where data is at national level providing information on patients with learning disabilities and/or autism spectrum disorder receiving inpatient care commissioned in England. Where possible, data is also provided an CCG and provider level

This is the first annual release to bring together data on learning disabilities and/or autism from various sources. Analysing the Assuring Transformation data using a years’ worth of records allows a greater depth of analysis.

### Accuracy and reliability

*This dimension covers, with respect to the statistics, their proximity between an estimate and the unknown true value.*

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<sup>36</sup> Data quality for any other data sources can be found on the relevant publication page. Links are provided in the introduction.

<sup>37</sup> <http://ec.europa.eu/eurostat/documents/64157/4392716/ESS-QAF-V1-2final.pdf/bbf5970c-1adf-46c8-afc3-58ce177a0646>

<sup>38</sup> <https://www.statisticsauthority.gov.uk/monitoring-and-assessment/code-of-practice/>

## Accuracy

For Assuring Transformation the data are collected via the Clinical Audit Platform (CAP) which allows a number of validations to be built in<sup>39</sup>. The system has been designed central to the patient using NHS number and date of birth as unique identifiers. The system is set up such that:

- For each NHS number there can only be one open episode of care during the period
- There can be multiple closed episodes of care for each NHS number within a period
- The system is 'live' and commissioners are expected to change information in the system as and when
- HSCIC analysts take a 'snap shot' of the system and use this for reporting. For this report the position at the end of March 2016 was used to determine the flow of patients up to 29 February 2016. Taking a late snapshot allows for late data submissions to be included in the analysis.

On a quarterly basis, HSCIC make use of the Personal Demographics Service (PDS)<sup>40</sup> to trace the home postcode of patients in care to then allow distance from home to be calculated. As part of the returned traced data we receive the traced date of birth. Table 4 shows that in 98% of cases, the age would remain the same following tracing.

**Table 4: differences in date of birth and age following use of the Personal Demographic Service<sup>41</sup>**

	Number of records	Percentage of records	
		where date of birth matched	where the age matched
Open episodes at the end of February 2016	2,650	95%	98%
Aged under 18 on admission	485	95%	98%

Source: Learning Disability Statistics – Annual overview

As is standard HSCIC practice, all figures in the reference data tables were independently checked. All figures in the report and Executive Summary were also independently checked.

Figures quoted from other data sources have already been pre-released unless otherwise stated and adhere to comparable accuracy and reliability checks.

## Reliability

CCGs and Hubs are expected to keep records up to date on an ongoing basis. There are two ways that HSCIC can currently assess if a CCG/Hub has done this:

1. Has the CCG/Hub made any alterations to any of the records during the period? Or created any new records;
2. If no records have been altered (due to no change in patient circumstances) then has the CCG/Hub selected the 'submission confirmation' option to confirm that their data is correct for this period?

<sup>39</sup> The validation rules can be viewed under section 4 of the 'instruction and guidance notes' found on the Assuring Transformation web page <http://www.hscic.gov.uk/assuringtransformation>

<sup>40</sup> <http://systems.hscic.gov.uk/demographics/pds>

<sup>41</sup> Where a traced data of birth could not be obtained, this was classed as a non-match. In some cases, date of birth did not match, however age was still the same at the point of measurement.

For the March 2016 snapshot that was used in this report, of the 219 HUBs and CCGs<sup>42</sup> 201 made submitted of confirmed a null submission, 15 neither and 3 have never had any patients in scope since HSCIC took over the collection.

## Timeliness and punctuality

*Timeliness refers to the time gap between publication and the reference period. Punctuality refers to the gap between planned and actual publication dates.*

Assuring Transformation data (which makes up the bulk of the analysis in this report) is published monthly and quarterly. Monthly to allow the most timely data to be released, and quarterly for more detailed analysis. This is the first time an annual report could be compiled from Assuring Transformation data since the transfer of the collection to HSCIC in from February 2015. This annual report focuses on the period between March 2015 and February 2016. Data from March 2016 has been used to provide the most up to date figures and allows for late submissions by commissioners.

## Accessibility and clarity

*Accessibility is the ease with which users are able to access the data, also reflecting the format in which the data are available and the availability of supporting information. Clarity refers to the quality and sufficiency of the metadata, illustrations and accompanying advice.*

Data for this annual release are published in Excel reference data tables and machine readable CSV files. A constructions and derivations file provides clarity to how measures were created. This written report provides background and further commentary on the key points from the analysis.

## Coherence and comparability

*Coherence is the degree to which data which have been derived from different sources or methods but refer to the same topic are similar. Comparability is the degree to which data can be compared over time and domain.*

Reference data table 1 draws together data on people with learning disabilities and/or autism from various sources and aims to give context to their differences in scope and time frame.

## Trade-offs between output quality components

*This dimension describes the extent to which different aspects of quality are balanced against each other.*

To allow for the best data quality for the annual period between March 2015 and February 2016, HSCIC used data from the March 2015 snapshot to allow for late data submissions. It is anticipated that there will still continue to be late submissions for the annual period which could not be included here.

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<sup>42</sup> Hub stands for Commissioning Hubs and CCG stands for Clinical Commissioning Groups CCGs. For more information on the different roles of CCGs and Hub see: <http://www.england.nhs.uk/wp-content/uploads/2014/01/pss-manual.pdf>

## Assessment of user needs and perceptions

*This dimension covers the processes for finding out about users and uses and their views on the statistical products.*

Data collected and published as part of this release is used by commissioners and healthcare professionals and the public. HSCIC consulted with the 'Learning disability and autism information group' on the format and usability of an annual report. Comments and suggestions were incorporated where possible and/or appropriate.

## Performance, cost and respondent burden

*This dimension describes the effectiveness, efficiency and economy of the statistical output.*

This annual release uses data that has either already been published (non AT data sources) or analyses the Assuring Transformation data in a different way. No additional data collection has been needed to produce this report.

## Confidentiality, transparency and security

*The procedures and policy used to ensure sound confidentiality, security and transparent practices.*

All HSCIC releases are assessed for disclosure risk prior to publication using and disclosure controls are applied where appropriate to ensure the disclosure risk complies with the NHS Anonymisation Standard. Further details are provided in the 'data presentation' section of this report.

Please see links below to relevant HSCIC policies:

Statistical Governance Policy (see link in 'user documents' on right hand side of page)

<http://www.hscic.gov.uk/pubs/calendar>

Freedom of Information Process

<http://www.hscic.gov.uk/foi>

A Guide to Confidentiality in Health and Social Care

<http://www.hscic.gov.uk/confguideorg>

Privacy and Data Protection

<http://www.hscic.gov.uk/privacy>

**Published by the Health and Social Care Information Centre  
Part of the Government Statistical Service**

**Responsible Statistician**

Stephanie Gebert, Analytical Section Head

ISBN 978-1-78386-719-6

This publication may be requested in large print or other formats.

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