

Learning Disability Census Report

England 30 September 2015 experimental statistics



We are the trusted national provider of high-quality information, data and IT systems for health and social care.

www.hscic.gov.uk enquiries@hscic.gov.uk



This product may be of interest to the Department of Health, the Care Quality Commission, NHS England and Public Health England. It will also be of interest to commissioners and providers of in-patient and community-based services for people with learning disabilities and/or autistic spectrum disorder (including Asperger's Syndrome). Charities and third sector organisations with a focus on people with learning disabilities, and/or autistic spectrum disorder (including Asperger's Syndrome) as well as patients themselves, and their family and friends, may also find this product useful.

Author: Community and Mental Health Team

Health and Social Care Information Centre

Responsible statistician: Chris Buttery, Section Head

Version: V1.0

Date of publication: 15 December 2015

Contents

Executive Summary	
Key facts	8
Introduction	9
Structure of this report	9
Data presentation	10
Other data sources and future sources of Learning Disability Statistics	10
Background	13
Census criteria	14
England level findings – Patients counts	15
Profile of patients	16
Age, Gender and Ethnicity	17
Diagnostic category on census day	18
Profile of services provided	19
Ward service type	19
Ward service type by diagnostic category	20
Ward security level	20
Ward gender designation and facilities available	21
NHS/Independent provider	23
Reason for admission to, and being in, inpatient care	23
Mental Health Act, Guardianship & Deprivation of Liberty Safeguards (DoLS)	23
Legal status on census day by legal status on admission	24
Legal status on census day by ward security	25
The use of Deprivation of Liberty Safeguards (DoLS)	26
Main treatment reason for remaining in care on census day	26
Diagnostic category on census day	27
Behavioural risks	28
Experience of care	31
Incidents	31
Incidents by gender	32
Incidents by ward gender type	33
Incidents by main treatment reason	34
Medication	35

Antipsychotic drug use	35
Antipsychotic drug use and gender	36
Antipsychotic drug use and diagnosis	36
Antipsychotic drug use and incidents	37
Antipsychotic drug use and reason for administration	37
Rapid tranquilisation usage	38
Rapid tranquilisation and antipsychotic medication usage	38
Rapid tranquilisation and incidents	39
Treatment without consent by Second Opinion Approved Doctor (SOAD)	40
Use of independent advocacy	40
Use of an advocate and treatment without consent by Second Opinion Approve (SOAD)	ed Doctor 41
Care plan and discharge status	41
Details of the care plan	42
Care plan discussions	45
Care plan agreements	46
Family involvement	46
Length of stay and distance from home	46
Length of stay	47
Length of stay by age and gender	48
Length of stay by ward security level	48
Length of stay by provider type	48
Total length of stay	49
Distance from home	50
Distance from home by ward security	51
Distance from next of kin	51
Length of stay and distance from home	52
Geography	53
Region of hospital ward and region of residence	53
Comparing region of hospital ward and region of residence	54
Costs	56
Weekly cost by provider type	56
Weekly cost by type of organisation responsible for paying for patient care	57

Under 18s analysis	58
Main treatment reason for remaining in care for under 18s	58
Incidents for under 18s	59
Medication for under 18s	59
Advocacy usage for under 18s	60
Length of stay for under 18s	61
Distance from home for under 18s	63
Linking 2013, 2014 and 2015 Learning Disability Censuses	64
Patients receiving inpatient care at the time of 2014 census, but not receiving inpatient care at the time of the 2015 census	64
Approximate rate of discharge	65
Patients receiving inpatient care at the time of all 3 census collections	67
Patients receiving care at the time of all three census collections and changes in hos setting	spital 67
Patients receiving care at the time of all three census collections and distance from home	68
Patients receiving care at the time of all three census collections and ward security le	evel 70
Patients receiving care in all three census collections and care plan details	71
Patients receiving continuous inpatient care between the 2014 and 2015 census collections	72
Patients receiving continuous inpatient care between 2014 and 2015 census collection and incidents	ons 72
Patients receiving continuous inpatient care between 2014 and 2015 census collection	ons 73
Patients receiving continuous inpatient care between the 2014 and 2015 census	
collections and agreements	74
Linking the Learning Disability Census to Assuring Transformation	75
Scope differences	76
Differences by commissioner	77
All patients unreported in either collection	78
Patients unreported in either collection by region	79
Patients unreported in either collection by ward characteristics	80
Patients unreported in either collection by care plan	82
Patients unreported in either collection by Mental Health Act status on admission	82
Comparison of estimated totals for the 2013, 2014 and 2015	84

End note	86
Annex 1: Mental Health Act groupings used	87
Annex 2: Related reading	87

Executive Summary

This report presents initial findings from the 2015 Learning Disability Census. Data were collected via the Health and Social Care Information Centre (HSCIC) on behalf of the Department of Health, the Care Quality Commission, Public Health England and NHS England. This is the third Learning Disability Census; the previous two took place on 30 September 2013 and 2014 respectively. Information on the Learning Disability Census can be found at: http://www.hscic.gov.uk/ldcensus

The principal aim of the Learning Disability Census is to deliver action 17 in 'Transforming Care: A national response to Winterbourne View Hospital¹ - "an audit of current services for people with challenging behaviour to take a snapshot of provision, numbers of out of area placements and lengths of stay".

The Learning Disability Census provides an individual record-level snapshot of inpatients with learning disabilities, autistic spectrum disorder and/or behaviour that challenges, and the services they receive, for patients who were inpatients in NHS and independent sector services at midnight on 30 September 2015.

This initial release reports at England level on key findings of the 2015 Learning Disability Census. Where possible, comparisons are made within this report between 2014 and 2013 data. Further analysis reporting on geographical differences will be published in early 2016.

These statistics are important as they present definitive and comprehensive information about the population size, characteristics, and experience of care, of people whose treatment, care and support needs may be similar to those treated in Winterbourne View. The Learning Disability Census collected a range of information about this group of patients and their treatment environment, including demographics, ward characteristics and information relating to out of area placements and lengths of stay.

These statistics are intended to help inform improvements in the provision of inpatient and community-based care for people with learning disabilities, autistic spectrum disorders, and/or behaviour that challenges and will be of interest to mental health professionals as well as patients, their families and representative organisations.

The 2015 Learning Disability Census presents a significant opportunity to undertake longer term monitoring of change and outcomes and to compare the changing shape of inpatient care since 2013.

In January 2015, NHS England transferred responsibility to HSCIC for the collection and dissemination of the Assuring Transformation² collection. This is a commissioner based collection. Data are provided by English commissioners and healthcare is typically provided in England (although care commissioned in England and provided elsewhere in the UK will be included). These two datasets have been linked to help understand the differences between the two collections.

Transforming Care: A national response to Winterbourne View Hospital:
 https://www.gov.uk/government/publications/winterbourne-view-hospital-department-of-health-review-and-response
 More information on Assuring Transformation can be found here:
 https://www.hscic.gov.uk/assuringtransformation

Key facts³

Responses from 89 provider organisations were received on behalf of 3,000 patients who met the inclusion criteria for the 2015 Learning Disability Census. This figure is broadly in line with the previous two census collections; there were 3,250 inpatients on census day 2013 and 3,230 on census day 2014.

Key facts for 2015 show that on the 30 September 2015:

Reason for being in inpatient care

• For 2,340 patients (78%), the main treatment reason for being in inpatient care on census day was either due to a continuing behavioural treatment programme (690 patients, 23%), the continuing need for inpatient care of mental illness (1,155 patients, 39%), or where current behaviour has been assessed as being too high risk for the Ministry of Justice to agree any reduction in security level (495 patients, 17%).

Experience of care

- On census day in 2015, 2,155 patients (72%) had received antipsychotic medication either regularly or as needed in the 28 days prior to the census collection, compared to 2,345 patients (73%) in 2014.
- In 2015, 1,670 patients (56%) had one or more incidents reported in the three months prior to census day, compared to 1,780 (55%) in 2014. Incidents comprise: self-harm, accidents, physical assault, restraint or seclusion.

Distance from home and length of stay

Average length of stay and distance from home remained stable between the three censuses. Average⁴ length of stay on census day 2013, 2014 and 2015 respectively was of 542 days, 547 days and 554 days. The median distance from home on census day 2013, 2014 and 2015 was 34.5km, 34.4km and 38.6km respectively.

Patients receiving care at the time of all three census collections

• Of the 3,000 people receiving inpatient care on census day 2015; 1,450 patients (48%) were receiving care at the time of all 3 censuses; approximately 640 patients (21%) appeared in 2013 or 2014 census collections but not all 3 censuses; and 915 patients (30%) were receiving care at the time of the 2015 census only.

Comparison with Assuring Transformation⁵

Linking the two collections at patient level, 2,140 patients were common to both collections; 855 patients who appeared in the Learning Disability Census did not appear in the Assuring Transformation Collection; while 480 patients from the Assuring Transformation collection did not appear in the Learning Disability Census. Adding the unreported patients as identified by Assuring Transformation to the 2015 headcount puts the figure who were inpatient on census day 2015 closer to 3,480.

³ Due to rounding, percentage figures may not add up and adding suppressed data may not match a total figure.

⁴ Median averages are shown here; Reference data table 11 also shows the mean plus other breakdowns.

⁵ This uses the data for September as published in the October report http://www.hscic.gov.uk/pubs/ldsmoct15

Introduction

This report presents initial findings from the Learning Disability Census 2015. The census collected record-level information about patients with a learning disability, autistic spectrum disorder (including Asperger's syndrome) and/or behaviour that challenges, who were inpatients at midnight on 30 September 2015. Where appropriate, comparisons are made with the 2014 or 2013 Learning Disability Census. Results are at England level, further analysis at regional level will be published in early 2016.

Structure of this report

Information collected in the 2015 census is analysed here and where appropriate, compares the position to the 2014 or 2013 census. The chapters are split into:

- Profile of patients
- Profile of services provided
- Reason for admission to, and being in, inpatient care
- Experience of care
- Use of independent advocacy
- Care plan and discharge status
- Length of stay and distance from home
- Geography
- Costs
- Under 18s analysis
- Linking the 2013, 2014 and 2015 Learning Disability Censuses
- Linking the 2015 Learning Disability Census to Assuring Transformation
- Comparison of estimated totals for the 2013, 2014 and 2015

Each chapter contains descriptive statistics alongside commentary and then cross-tabulation with other measures as needed. The report is structured so that the cross-tabular analysis is presented in more depth as the reader navigates through the report. For example, the chapter 'Length of stay and distance from home' would consider measures identified in the 'Experience of care' section, but the 'Experience of care' section would not consider measures within the 'Length of stay and distance from home' chapter.

NHS numbers were included in the data items collected each year. This has allowed for data from all three census collections to be linked so direct comparisons to those who have been in inpatient care for all census collections can be made. Linking on NHS number between the 2015 Learning Disability Census and Assuring Transformation has allowed for more precise analysis of the number differences between the two collections.

Data presentation

In order to minimise the disclosure risk associated with small numbers, **all figures** presented within this report and within the reference data tables have had the following measures applied:

- Values of 0-4 have been replaced by *;
- Values have been rounded to the nearest 5;
- Percentage calculations 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 do not match the sum of the subtotals within the same table.

The 2013 Learning Disability Census is referenced throughout this report and is presented in the unsuppressed format it was reported in at the time. Any new breakdowns for the 2013 data have been suppressed.

For all census collections, records were sent to the HSCIC Personal Demographics Service (PDS) for NHS number verification and to trace a last known postcode of residence where that supplied by providers was invalid or unknown. Date of birth and gender were also returned from PDS. This is described in more detail in the Background Methodology and Data Quality Report⁶.

The 2013 Learning Disability Census report was unable to use the more accurate age information obtained through tracing in time for publication. However the revised ages were used in the 2014 report and are used here again, therefore information on patient ages for 2013 Learning Disability Census published within this report is not directly comparable with that published in the 2013 reports.

Additional documents in this publication cover the background to the report, data quality and methodology and census questions used.

The question set

The questions, including guidance notes for each census collection can be found on the HSCIC website⁷. The 2015 Census used the same structure as the 2014 Census to allow for comparison between collections, only one new questions was added; new validations were added to ensure better data quality at submission.

Other data sources and future sources of Learning Disability Statistics

Assuring Transformation

In January 2015, NHS England transferred responsibility to HSCIC for the collection, analysis and dissemination of the Assuring Transformation collection. This is a commissioner based collection, data are provided by English commissioners and healthcare is typically provided in England (although care commissioned in England and provided elsewhere in the UK will be included). These two datasets have been linked to help understand the differences between the results of the two collections. The results are presented in the section 'Linking the 2015 Learning Disability Census to Assuring Transformation'

⁶ http://www.hsc<u>ic.gov.uk/pubs/ldcensus15</u>

⁷ http://www.hscic.gov.uk/article/6468/Reports-from-the-Learning-Disability-Census-collections

Mental Health and Learning Disabilities Dataset (MHLDDS)

Information on learning disabilities is now included in the Mental Health and Learning Disabilities Data Set (MHLDDS) effective from September 2014. This dataset will expand from January 2016 to become the Mental Health Services Dataset (MHSDS) and it is expected key data items from the Learning Disability Census will be extracted from this collection. The MHLDDS collects a range of information about care delivered to users of NHS funded secondary mental health and learning disabilities services for adults and older people in England.

MHLDDS data for August 2015 reported 57,149 people in contact with Learning Disability Services and 1,534 people were in a Learning Disabilities ward.

Relevant reports

Building the right support⁸

Published October 2015, this report provides a framework for commissioners to develop more community services and includes information on the Transforming Care Partnerships that are leading service re-design across England. The report identifies an approach to reduce use of inpatient facilities in favour of a range of new community based services.

Supporting people with a learning disability and/or autism who display behaviour that challenges, including those with a mental health condition⁹

Published October 2015 this report provides a service model for commissioners of health and social care services. It seeks to outline what good services for people with learning disabilities and/or autism should look like. It builds on reports by Mansell (2007)¹⁰ and Valuing People Now¹¹, and describes developing high quality local services that may reduce the reliance on out-of-area placements.

Transforming Care for People with Learning Disabilities - Next Steps

Published July 2015¹², this is a progress report from the Transforming Care Delivery Board – it provides an update on work being delivered by the national Transforming Care Delivery Board partners: NHS England, Local Government Association, the Department of Health, Association of Directors of Adult Social Services, Care Quality Commission and Health Education England. The report recognises the scale of the change required, and seeks to address underlying factors associated to "why so many people remain in, and are continuing to be placed in, hospital settings." The report identifies establishment of fast-track sites with access to additional support, including a £10 million transformation fund to use new approaches, address enduring issues and drive system change.

 $\underline{\text{http://webarchive.nationalarchives.gov.uk/+/www.dh.gov.uk/en/publicationsandstatistics/publications/publicationspublicat$

⁸ https://www.england.nhs.uk/wp-content/uploads/2015/10/ld-nat-imp-plan-oct15.pdf

https://www.england.nhs.uk/wp-content/uploads/2015/10/service-model-291015.pdf

¹¹ https://www.gov.uk/government/uploads/system/uploads/attachment_data/file/215891/dh_122387.pdf

https://www.england.nhs.uk/wp-content/uploads/2015/01/transforming-care-progress-report.pdf

Winterbourne View: Transforming Care Two Years On

This report aims to establish the position two years on from the report 'Transforming care: A national response to Winterbourne View hospital' 13. It considers progress made towards commitments set out in this report along with work still to be done. The report is a joint collaboration between Department of Health, NHS England, Local Government Association, Care Quality Commission, Health and Social Care Information Centre and Public Health England.

Winterbourne View - Time for change

Transforming the commissioning of services for people with learning disabilities and/or autism¹⁴: this report, published in November 2014, used contemporary figures reported by NHS England¹⁵ that identified that there were 2,600¹⁶ inpatients reported by commissioners and asserted that for many patients, admissions may have been preventable and hospital stays could have been shorter with discharge to community accommodation (given appropriate community support being in place).

https://www.gov.uk/government/uploads/system/uploads/attachment_data/file/213215/final-report.pdf

http://www.england.nhs.uk/wp-content/uploads/2014/11/transforming-commissioning-services.pdf

http://www.england.nhs.uk/ourwork/qual-clin-lead/ld/atd/

¹⁶ Assuring Transformation data was used

Background

The BBC One Panorama programme "Undercover Care: The Abuse Exposed" 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 and a series of publications by the Department of Health. 19

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.

The Learning Disability Census was commissioned as one 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. The signatories to the Department of Health 'Winterbourne View Review Concordat: Programme of Action²⁰' ('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.

The HSCIC undertook the first Learning Disability Census on 30 September 2013 and published reports in December 2013 and April 2014. In accord with the timetable of actions the census was repeated in 2014 and now again in 2015 to enable the Transforming Care Assurance Board to be informed and assess the extent to which change and progress had been achieved.

This report is the first in a series of two detailing information from the 2015 Learning Disability Census. It represents data received from a 98% response from providers of inscope services. It will provide data users with a clear overview at national level of the position concerning the treatment and care of people who are within definitional scope from the providers of such services in England. The second report will consider the data received at a more granular sub-national level.

Concordat actions were intended to lead to a rapid reduction in hospital placements for this group of people by 1 June 2014, stating:

"People should not live in hospital for long periods of time. Hospitals are not homes."

The data in the 2013 and 2014 census suggest that this target may have been overambitious given the complexity of needs of patients using diverse inpatient settings. The number of patients subject to formal detention has remained comparable between all three censuses, the conclusion being that transferring or discharging patients who are detained may be more challenging.

This report is intended to:

¹⁷ http://www.bbc.co.uk/programmes/b011pwt6_Note: the program is no longer available

¹⁸ http://hosted.southglos.gov.uk/wv/report.pdf

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

https://www.gov.uk/government/uploads/system/uploads/attachment_data/file/213217/Concordat.pdf

- Enable comparison of the experience of care between 2013, 2014 and 2015;
- Indicate where change has, or has not, been evidenced;
- Highlight issues with the quality of care that people are receiving;
- Quantify the extent to which people are using services for protracted periods;
- Establish how many people are receiving services far from their home or usual communities.

Actions identified within 'Transforming Care' and 'Concordat' are expected to benefit from being informed by findings from this census and the previous censuses.

Census criteria

The census collected information on inpatients receiving treatment or care in a facility registered with the Care Quality Commission as a hospital operated by either an NHS or independent sector provider who provides mental or behavioural healthcare in England.

Record level returns reflect only inpatients (or individuals on leave with a bed held vacant for them) at midnight on 30 September 2015. The individual will have 'a bed' normally designated for the treatment or care of people with a learning disability or will have 'a bed' designated for mental illness treatment or care and will be diagnosed with or understood to have a learning disability and or autistic spectrum disorder and/or behaviour that challenges.

The following criteria were used to assess if a patient's details submitted in the 2015 census were sufficient for the patient to be considered to be 'in scope':

A service user needed to meet at least one of these criteria identified in the question set:	Additional criteria
Question 17b:	admission date was
On census day was a diagnostic category of Learning Disability	on or before 30
(ICD-10 codes F70 to F79) applicable to the patient?	September 2015
Question 17c:	
On census day was a diagnostic category of Autistic Spectrum	
Disorder including Asperger's Syndrome (ICD-10 codes F840, F841	
or F845) applicable to the patient?	
Question 36:	
Was the predominant service type of the ward Learning Disabilities?	
Question 17h:	
ICD-10 code of F84 (indicating autism)	

If none of these criteria were met then the patient was not included in the census analysis. For the 2015 census, 3,065 patient records were returned. After data cleansing, 65 did not meet the inclusion criteria and were removed from the analysis. This leaves a population size of 3,000 patients on census day 2015. The Background Methodology and Data Quality Report explains more about data cleansing undertaken.

England level findings – Patients counts

This report aims to draw out the overall picture for the 2015 Learning Disability Census in comparison to both the 2013 and 2014 Learning Disability Censuses. Patients who were reported on in each of the census collections have had their information from each collection linked.

There were 3,000 patients considered to be in-scope for the 2015 Learning Disability Census, this compares to 3,230 patients for the 2014 Learning Disability Census and 3,250 patients for the Learning Disability Census 2013.

Linking the 2015 census patient data using NHS number to the 2013 and 2014 censuses patient data indicated that 1,450 patients were receiving inpatient care on census day in all three years suggesting that 48% of people in the 2015 census were also receiving inpatient care at the time of the 2013 and 2014 censuses. This does not necessarily mean they will have been receiving continuous inpatient care throughout the whole period or that there was no movement between facilities. Figure1 illustrates the way the three census collections link together.

Linking the three census collections on NHS number and then analysing the admission dates provided for the 2015 Learning Disability Census indicated that there were 245 patients who had a first admission date (as part of a continuous period of inpatient care) prior to the 2014 census but who did not appear in the 2014 census. This suggested that they would have been receiving in-patient care at the time of the 2014 census and therefore that they were likely to have been eligible for inclusion in the census, however, they were not included by data providers. Additionally, 295 patients had a first admission date (as part of a continuous period of inpatient care) prior to the 2013 census but were not returned in the 2013 census.

This would have put the 2014 inpatient population closer to 3,475 and the 2013 inpatient population closer to 3,545. As there was no information collected during 2013 or 2014 for these individuals, the original count of 3,250 for the 2013 Learning Disability Census and 3,230 for the 2014 Learning Disability Census is used throughout this report. This enables comparisons between the three years by various measures.

The section 'Linking 2013, 2014 and 2015 Learning Disability Censuses' offers more detail, whilst the Background methodology and data quality report examines the way the linkage took place.

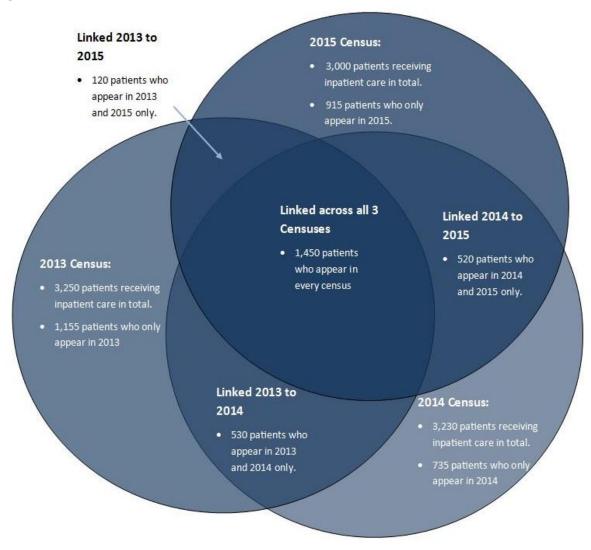


Figure 1: Links between the 2013, 2014 and 2015 census collections

Data Source: Learning Disability Census 2015. Data is not available in a reference table Base: All patients (3,250 in 2013, 3,230 in 2014, 3,000 in 2015)

Suppression rules: * represents a figure less than 5 that has been suppressed. See 'Introduction' for information on suppression rules. Due to suppression, figures may not sum.

Note: Analysing 'first admission' date information for returns to the 2015 census identified 245 patients who had an admission date prior to the 2014 census. 295 patients had an admission date prior to the 2013 census; this suggests that they would have been receiving inpatient care at the time of the 2013 or the 2014 census. This group of people fall within the groups receiving care in the 2015 census only (915 patients), Linked 2013 to 2015 (120 patients) or Linked 2014 to 2015 (520 patients). See the section on linking 2013, 2014 and 2015 Learning Disability Censuses for more information

Profile of patients

Reference data tables: 1, 2, 17

This section provides analysis on the results of questions:

- Q4. Age:
- Q5. Gender:
- Q6. Ethnicity;
- Q17b, c. Diagnostic category on census day.

Age, Gender and Ethnicity

The overall profile of patients remained mostly unchanged between the three Learning Disability Census collections. The ethnicity of patients was broadly in line with that of the English population, whereas the age and gender differ²¹.

- 6% of patients (165 patients) were aged 'Under 18', much lower than the comparable proportion of England's general population (24%);
- 92% of patients (2,755 patients) were aged 18-64, substantially higher than the comparable proportion England-wide (59%);
- 3% of patients (80 patients) were aged 65 and over, much lower than the comparable proportion for England (18%);
- 75% of patients (2,255 patients) were male, much higher than the comparable proportion for England (49%).

Table 1 shows the demographic split for patients receiving inpatient care at the time of the 2015 census.

Table 1: Number of patients by age, gender and ethnicity on census day 2013, 2014 and 2015

	2013	2014	2015
All patients	3,250	3,230	3,000
Gender			
Male	2,421	2,400	2,255
Female	829	830	740
Not Specified	-	-	*
By Age			
Under 18	160	160	165
18 - 34	1,605	1,600	1,490
35 - 64	1,414	1,405	1,265
65 and over	71	65	80
By Ethnicity			
White	2,720	2,750	2,535
Mixed	68	90	90
Asian or Asian British	114	120	115
Black or Black British	175	195	180
Other Ethnic Groups	34	25	30
Not Stated	122	35	25
Not Known	17	15	20

Data Source: Learning Disability Census 2015. Reference table 1

Base: All patients (3,250 in 2013, 3,230 in 2014, 3,000 in 2015)

Suppression rules: * represents a figure less than 5 that has been suppressed. See 'Introduction' for information on suppression rules. Due to suppression, figures may not sum.

Note: Data for 2013 includes updated information for age and gender since publication of the 2013 Learning Disability Census so figures may differ from those previously published. See 'data presentation'.

²¹ Population figures for England are taken from the ONS Population Estimates for UK, England and Wales, Scotland and Northern Ireland, Mid-2014. This is available as a zip file to download from: http://www.ons.gov.uk/ons/rel/pop-estimate/population-estimates-for-uk--england-and-wales--scotland-and-northern-ireland/mid-2014/rft--mid-2014-uk-population-estimates.zip age bands for the ONS estimates do not match exactly to those use by the Learning Disability Census, the groups used are: 0-19; 20-64; 65 and over.

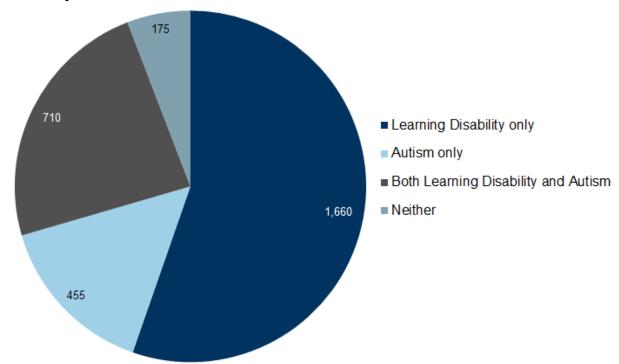
The value of these data lies in investigating whether elements of a services user's profile relate to the experience of care they receive. As such, age and gender are used throughout this report and in the reference data tables.

Questions were asked around whether a patient also had a hearing, sight or physical disability requiring a wheelchair as well as how they communicate. Whether a patient has additional special needs can affect the care they require and receive. This is not covered in depth in this report. However, results of these questions are provided in reference data table 2^{22} .

Diagnostic category on census day

On census day Reference data table 1 shows that in 2015, 2,370 patients (79%) were recorded as having a learning disability, and 1,160 patients (39%) were recorded as having autism; 710 patients (24%) were recorded as having both diagnoses. 175 patients (6%) were not recorded as having either.²³ Figure 2 illustrates how these diagnoses overlap.

Figure 2: Number of patients formally diagnosed with a learning disability and/or autism on census day 2015



Data Source: Learning Disability Census 2015. Reference table 1

Base: All patients (3,000)

Suppression rules: * represents a figure less than 5 that has been suppressed. See 'Introduction' for information on suppression rules. Due to suppression, figures may not sum.

18

²² Analysis of the 2014 data showed some anomalies within the data such as females being on a male ward. To counteract this, online validations were put in place for the 2015 Learning Disability Census. See 'Background methodology and data quality report' for the full list of validations that took place at data entry.

²³ See the 'Census criteria' section for in scope criteria. Reference data table 1 for the figures

Profile of services provided

Reference data tables: 3, 17

This section provides analysis on the results of questions:

- Q36. Ward service type;
- Q38. Ward security level;
- Q29. Ward gender designation;
- Q30-32. Single sex areas available on mixed wards;
- Q8. NHS/ Independent provider.

Ward service type

On census day in 2015, 2,255 patients (75%) were on a ward designated for people with learning disabilities, compared with 2,390 patients (74%) in the 2014 census collection. The 2015 census also showed there were 665 patients (22%) on a ward designated for mental health and 80 patients (3%) were on 'other wards'. A patient's learning disability may not be related to their mental health care needs and therefore wards other than those specifically for patients with learning disabilities may be more appropriate for their inpatient care.

The report 'Reasonably Adjusted'²⁴ identified that while some good practice was evident, few mental health services had comprehensively and systematically considered their practice and developed provision to ensure people with autism or learning disabilities achieved fair access and effective interventions. The revision to the 'Green Light Toolkit (2004)' in 2013²⁵ recognised that some services were failing to fully meet their responsibilities under equalities legislation, but significantly that, where appropriate, people who have learning disabilities or autism should have equality of access to mainstream mental health services.

Table 2: Number and percentage of patients by ward service type on census day 2013, 2014 and 2015

		Number			Percent	
	2013	2014	2015	2013	2014	2015
Total	3,250	3,230	3,000	100%	100%	100%
Learning Disability	2,481	2,390	2,255	76%	74%	75%
Mental Health	653	755	665	20%	23%	22%
Other	116	85	80	4%	3%	3%

Data Source: Learning Disability Census 2015. Reference table 3 Base: All patients (3,250 in 2013, 3,230 in 2014, 3,000 in 2015)

Suppression rules: * represents a figure less than 5 that has been suppressed. See 'Introduction' for information on suppression rules. Due to suppression, figures may not sum.

²⁴ http://www.ndti.org.uk/uploads/files/NHS_Confederation_Report.pdf

http://www.ndti.org.uk/uploads/files/Green_Light_Toolkit_22_Nov_2013_final.pdf

Ward service type by diagnostic category

Figure 3 compares the ward service type by the diagnostic category of the patients on the ward. Of the 1,660 patients diagnosed with learning disabilities only, 1,305 (79%) were receiving care on a learning disabilities ward. 605 patients (85%) of the 710 diagnosed with both learning disabilities and autism were receiving care on a learning disabilities ward; of the 455 patients diagnosed with autism only, 240 patients (53%) were receiving care on a mental health ward.

No. of patients Learning disability only 1,400 Autism only 1,200 Both Learning disability and Autism 1,000 Neither 800 1.305 600 400 605 200 330 240 170 170 25 40 20 0 Learning disability ward Mental health ward Other ward

Figure 3: Number of patients per ward service type and diagnostic category on census day 2015

Data Source: Learning Disability Census 2015. Reference table 17 Base: All patients (3,000)

Suppression rules: * represents a figure less than 5 that has been suppressed. See 'Introduction' for information on suppression rules. Due to suppression, figures may not sum.

Ward security level

Table 3 shows that on census day in 2015, 1,575 patients (53%) were receiving care in general wards; the highest proportion in all three census collections. The proportion of patients receiving care in low secure wards reduced to 27% (810 patients) compared to 37% (1,195 patient) and 31% (1,015 patients) on census day 2013 and 2014 respectively. Otherwise, the split between the different ward security levels remains unchanged between 2013, 2014 and 2015 census collections²⁶.

Ward service type

Ward security can play a key role in determining where in the country a service user is placed. For example, there are fewer high secure hospitals than hospitals with lower levels

²⁶ PICU was a new option for the question on ward security level in the 2014 Learning Disability Census and remained for the 2015 collection.

of security. The section 'Distance from home and length of stay' below touches on this topic, and the 2015 Census further analysis report (due for release early 2016) will explore this in more detail.

Table 3: Numbers and percentage of patients by ward security level on census day 2013, 2014 and 2015

		Number			Percent	
	2013	2014	2015	2013	2014	2015
Total	3,250	3,230	3,000	100%	100%	100%
General	1,470	1,555	1,575	45%	48%	53%
Low Secure	1,195	1,015	810	37%	31%	27%
Psychiatric Intensive Care Unit ^	-	40	25	-	1%	1%
Medium Secure	512	550	525	16%	17%	17%
High Secure	73	70	70	2%	2%	2%

Data Source: Learning Disability Census 2015. Reference table 3

Base: All patients (3,250 in 2013, 3,230 in 2014 and 3,000 in 2015)

Suppression rules: * represents a figure less than 5 that has been suppressed. See 'Introduction' for

information on suppression rules. Due to suppression, figures may not sum.

Ward gender designation and facilities available

The 2013 Learning Disability Census report made reference to the Department of Health report on eliminating single sex accommodation in hospitals²⁷. This report stated that if a hospital does have mixed sex wards, it needs to provide single sex day, sleeping, and bathing spaces. The Care Quality Commission have issued a supporting note that identifies circumstances where mixed sex accommodation can be considered compliant²⁸. There was little change between the three census collections on the use of mixed and single sex wards.²⁹

Females were more likely than males to be receiving care on a mixed gender ward. 38% of females (280) were on a mixed gender ward in 2015 compared to 20% of males (445).³⁰

Figure 4 shows access to single sex facilities for those in a mixed gender ward. The number of patients on a mixed ward who had access to all 3 single sex facilities (sleeping, bathing and day areas) decreased from 580 patients in the 2014 Learning Disability Census collection (68% of those in mixed sex wards) to 540 patients in the 2015 Learning Disability Census collection (74% of those on mixed sex wards). The number of patients with no single

http://www.cqc.org.uk/sites/default/files/documents/supporting_note_mixed_sex_accommodation_for_external_publication.pdf

[^]PICU was included under 'Low Secure' in the 2013 census.

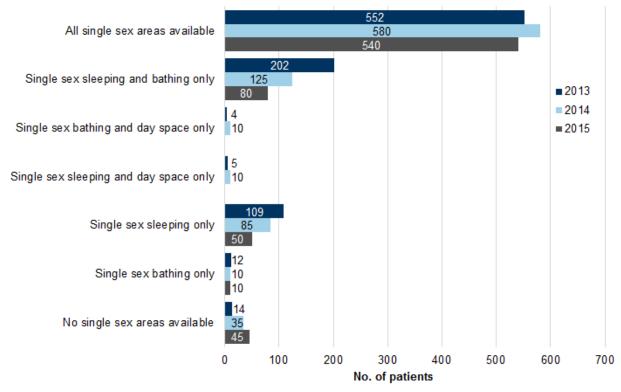
²⁷ Eliminating mixed sex accommodation in hospitals, Department of Health, 2010: https://www.gov.uk/government/publications/eliminating-mixed-sex-accommodation

²⁹ In the 2014 census there were 20 patients reported to be on the incorrect ward for their gender; for the 2013 census, there were 15 patients on the wrong gender ward. This was understood to be a coding error. Patients recorded as being on the wrong gender ward were removed from this part of the analysis. For 2015 a validation was added to stop these coding errors.

³⁰ Reference data table 3 displays this information. Percentage figures can only be approximated from the reference data table due to rounding

sex space of any kind continued to increase to 45 patients (6%) on census day 2015 from 14 patients on census day 2013 (2%) and 35 patients on census day 2014 (4%).

Figure 4: Number of patients receiving care on a mixed sex ward who have access to single sex facilities on census day 2013, 2014 and 2015

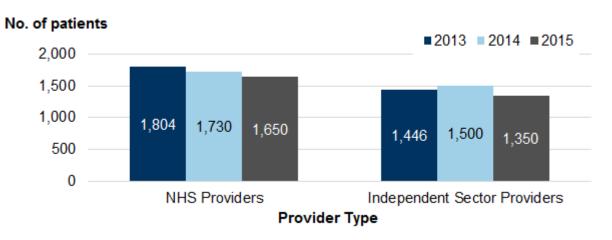


Data Source: Learning Disability Census 2015. Reference table 3
Base: All patients on a mixed sex ward (898 in 2013, 855 in 2014, 725 in 2015)
Suppression rules: * represents a figure less than 5 that has been suppressed. See 'Introduction' for information on suppression rules. Due to suppression, figures may not sum.

NHS/Independent provider

Figure 5 compares NHS and independent providers and shows that on census day in 2015, 1,650 patients (55%) were receiving inpatient care with NHS providers, compared to 1,730 patients (54%) on census day in 2014.

Figure 5: Number of patients per provider type on census day 2013, 2014 and 2015



Data Source: Learning Disability Census 2015. Reference table 3
Base: All patients (3,250 in 2013, 3,230 in 2014, 3,000 in 2015)
Suppression rules: * represents a figure less than 5 that has been suppressed. See 'Introduction' for information on suppression rules. Due to suppression, figures may not sum.

Reason for admission to, and being in, inpatient care

Reference data tables: Table 4, 5, 17, 18, 19

This section provides analysis on the results of questions:

- Q11. Use of the Mental Health Act on census day;
- Q12. Use of the Mental Health Act on admission day:
- Q14. Deprivation of Liberty Safeguards (DoLS);
- Q17a. Main treatment reason for remaining in hospital on census day;
- Q17d-g. Diagnostic category on census day;
- Q18a-g. Behavioural risks (such as violence and fire setting).

This section considers why a person came into inpatient setting and why they stayed there. The section on 'Care plan and discharge status' provides additional information as to why patients remain in inpatient care as per the details of the care plan.

Mental Health Act, Guardianship & Deprivation of Liberty Safeguards (DoLS)

The proportion of inpatients subject to the use of the Mental Health Act (MHA) on census day as reported in 2015 saw a rise compared to 2013 and 2014 census collections. 83% of

patients (2,500 patients) were subject to the MHA on census day 2015 compared to 78% of patients (2,536 patients) in 2013 and 80% of patients (2,585) in 2014.

Figure 6 shows the proportion of inpatients subject to MHA on each census day. For the 2015 census, of the 2,500 patients (83%) subject to MHA, 1,375 patients (46%) were detained under Part II, 405 patients (13%) were detained under Part III without a restriction order, and 645 patients (21%) were detained under Part III and subject to Ministry of Justice restriction order. 80 patients (3%) were classified as 'Other' which includes the use of Guardianship (Guardianship is part of the MHA section 7) and DoLS.

Disaggregated figures for the use of the MHA orders are provided in reference data table 4. The groupings used for this analysis can be found in the annex of this report.

Reference data table 4 also shows that only 10 patients were subject to a Guardianship order. These are intended to help a patient live as independently as possible and also provide a legal framework to oversee their care in the community.

The MHA grouping used in this report allows for the identification of patients formally detained under Part III with a restriction order. This is important since these patients cannot be discharged from hospital even for periods of extended leave or transferred to another hospital without the agreement of the Ministry of Justice³¹.

2013 22% 45% 12% 19% 2% 2014 45% 13% 20% 20% 2015 21% 17% 46% 13% 3% 0% 20% 40% 60% 80% 100% MHA Part II ■MHA Part III with no restrictions ■MHA Part III with restrictions Other ■ Informal

Figure 6: Percentage of patients detained under the Mental Health Act on census day 2013, 2014 and 2015

Data Source: Learning Disability Census 2015. Reference data table 4 Base: All patients (3,250 in 2013, 3,230 in 2014, and 3,000 in 2015)

Suppression rules: * represents a figure less than 5 that has been suppressed. See 'Introduction' for

information on suppression rules. Due to suppression, figures may not sum.

Legal status on census day by legal status on admission

Table 4 compares legal status on admission to legal status on census day. The same groupings are used as above.

2,455³² patients had the same type MHA status on admission as on census day 2015 (this does not include the 'Other' category which is an amalgamation of several MHA sections). 140 patients who were admitted informally became subject to the Act whilst receiving

-

³¹ These groups were introduced for the 2014 census following stakeholder and user feedback

³² This is calculated from summing the unsuppressed figures, summing the suppressed data may give slightly different results due to rounding.

inpatient care. However, 125 patients who entered the inpatient setting under the MHA were receiving care informally by census day.

Note the above does not exclude the possibility that there could have been other Legal Statuses applied to a patient between admission and census day.

Table 4: Number of patients by legal status on census day 2015 compared to legal status on admission 2015

		Legal status on census day					
	All patients	Informal	MHA Part II	MHA Part III with no restrictions	MHA Part III with restrictions	Other	
otal	3,000	500	1,375	405	645	80	
Legal status on admission							
Informal	510	370	130	5	5	,	
MHA Part II	1,395	125	1,215	20	30	10	
MHA Part III with no restrictions	405	*	10	330	60	5	
MHA Part III with restrictions	620	*	5	50	545	20	
Other	65	*	15	*	*	45	

Data Source: Learning Disability Census 2015. Reference data table 18

Base: All patients (3,000)

Suppression rules: * represents a figure less than 5 that has been suppressed. See 'Introduction' for information on suppression rules. Due to suppression, figures may not sum.

Legal status on census day by ward security

Comparing legal status to the ward security level, Table 5 shows that of those receiving care on a general ward, 470 patients (30%) were receiving care informally, the rest of the patients were under a section of the MHA. 53% (835 patients) were detained under MHA Part II. 140 patients (9%) were detained under the MHA Part III with a restriction order. Of those receiving care on a high secure ward, 45 patients (68%) were detained under the MHA Part III and subject to a restriction order.

Table 5: Number of patients by legal status on census day 2015 and ward security level

	Legal status on census day						
	All patients	Informal	MHA Part II	MHA Part III with no restrictions	MHA Part III with restrictions	Other	
Total	3,000	500	1,375	405	645	80	
Ward security level							
General	1,575	470	835	105	140	20	
Low Secure	810	10	340	175	265	20	
PICU *	25	*	20	*	*	*	
Medium Secure	525	20	170	115	190	30	
High Secure	70	*	5	10	45	5	

Data Source: Learning Disability Census 2015. Reference data table 18

Base: All patients (3,000)

Suppression rules: * represents a figure less than 5 that has been suppressed. See 'Introduction' for information on suppression rules. Due to suppression, figures may not sum.

The use of Deprivation of Liberty Safeguards (DoLS)

Deprivation of Liberty Safeguards (DoLS) legislation under the Mental Capacity Act may be used in certain circumstances rather than the MHA when someone does not have capacity to make their own decisions about being deprived of their liberty. Reference data table 4 shows that on census day 2015, 195 patients (6%) were subject to DoLS. Compared to 2013 this is a 487% increase which may be due to the Supreme Court decision in Cheshire West³³.

Reference data table 17 shows that on census day in 2015, 26% (20 patients) of those aged 65 and over were subject to a DoLS authorisation. This figure is much higher than for any other age category, which is likely to reflect the prevalence of dementia amongst the over 65s.

Main treatment reason for remaining in care on census day

The three most common main treatment reasons for remaining in inpatient care on census day 2015 were:

- Current behaviour assessed as too risky for Ministry of Justice to agree any reduction in security level (495 patients, 17%);
- Continuing need for inpatient care of mental illness (1,155 patients, 39%);
- Continuing behavioural treatment programme (690 patients, 23%).

All figures are in line with the results of the 2014 census³⁴. The report authored by Sir Stephen Bubb³⁵ in 2014 suggested that insufficient community based support and provision of accommodation was a factor in people remaining in inpatient facilities. Building the right

https://www.supremecourt.uk/decided-cases/docs/UKSC_2012_0068_Judgment.pdf

This question was not asked in 2013

³⁵ http://www.england.nhs.uk/wp-content/uploads/2014/11/transforming-commissioning-services.pdf

support³⁶ published in October 2015 builds on this and outlines NHS England's approach to reshaping provision to close traditional inpatient facilities and develop community based alternative services. The challenge in this reshaping of provision is the extent to which accommodation can be developed that is suited to those current inpatients who are in hospital for the treatment reasons indicated above whist meeting the reduction targets suggested in the above reports.

The 2015 census data suggest that 2,340 patients (78%) were assessed as needing to remain as inpatients and therefore raises a question as to what other reasons there are which were keeping the remainder of patients in inpatient care. This applied to 380 patients (13%) who did not need inpatient care according to treatment reason and 280 patients (9%) who had 'Other' recorded for their main treatment reason.

Table 6: Number and percentage of patients by main treatment reason for being in inpatient care on census day 2014 and 2015

	Numbe	Number		ent
	2014	2015	2014	201
al Carl	3,230	3,000	100%	100%
Need inpatient care for treatment reason	2,545	2,340	79%	78%
of which:				
Current behaviour assessed as too risky for Ministry of Justice to agree any reduction in security level	485	495	15%	17%
Continuing need for inpatient care of mental illness	1,365	1,155	42%	39%
Continuing behavioural treatment programme	695	690	21%	23%
Do not need inpatient care for treatment reason	440	380	14%	13%
of which:				
Local step-down placement in inpatient psychiatric unit preparatory to community resettlement being actively sought	200	170	6%	6%
New community placement actively being sought as previous placement no longer viable	230	200	7%	7%
Residential care placement funding dispute	10	10	0%	0%
Other	245	280	8%	9%

Data Source: Learning Disability Census 2015. Reference data table 5

Base: All patients (3,230 in 2014, 3,000 in 2015)

Suppression rules: * represents a figure less than 5 that has been suppressed. See 'Introduction' for

information on suppression rules. Due to suppression, figures may not sum.

Note: This question was not asked in 2013

Diagnostic category on census day

The diagnostic category question asks whether the diagnosis was severe enough to require hospital treatment. Information on diagnosis of Learning disability and Autism was explored under the 'Profile of patients' section. The answer option for these did not include 'severe enough to require treatment' since these are not seen as reasons for inpatient treatment. Figure 7 shows that for each diagnostic category, on census day 2014 & 2015³⁷, very few patients were recorded as having a severe enough diagnosis to require treatment. For each category, over 70% of patients did not have this diagnosis at all.

³⁶ https://www.england.nhs.uk/wp-content/uploads/2015/10/ld-nat-imp-plan-oct15.pdf

This question was not asked in 2013

Combining all diagnoses together, reference data table 5 shows that 2,555 patients (85%) did not have any diagnosis severe enough to require treatment. 380 patients (13%) had one diagnosis severe enough to require treatment whilst 60 patients (2%) had two or more diagnosis severe enough to require treatment.

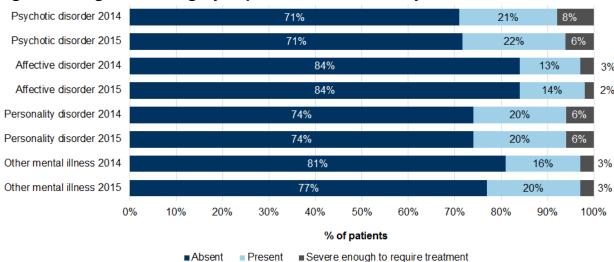


Figure 7: Diagnostic category of patients on census day 2014 and 2015

Data Source: Learning Disability Census 2015. Reference data table 5

Base: All patients (3,230 in 2014, 3,000 in 2015)

Suppression rules: * represents a figure less than 5 that has been suppressed. See 'Introduction' for

information on suppression rules. Due to suppression, figures may not sum.

Note: This question was not asked in 2013

Behavioural risks

Six questions were asked as to whether a patient was recorded to be at risk of certain behaviour types and whether the risk was absent, present or severe enough to require hospital treatment. Table 7 shows the results. On census day 2015, 2,505 patients (84%) were recorded as being at risk of at least one of the behaviour traits, although in only 805³⁸ cases was any individual risk in isolation considered sufficiently severe enough to require hospitalisation.

Considering each behaviour risk in turn and showing the results in order of decreasing prevalence³⁹:

- 2,120 patients (71%) were recorded as at being at risk of violence or threats of violence to others;
- 1,450 patients (48%) were recorded as being at risk of self-injury;
- 1,450 patients (48%) were recorded as being at risk of causing damage to property
- 1,060 patients (35%) were at risk of sexual behaviour constituting risk to others;
- 645 patients (22%) were at risk of sexual behaviour constituting risk to themselves;
- 435 patients (14%) were at risk of fire setting.

³⁸ Reference data table 5 shows this information. Percentage figures can only be approximated from the reference table due to rounding.

³⁹ The following figures were calculated from summing the unsuppressed figures, summing the suppressed data may give slightly different results due to rounding.

Table 7: Percentage of patients with each behavioural risk on census day 2014 and 2015

			e enough to	Severe enough to require treatment only
Any risk	2014	14%	86%	24%
•	2015	16%	84%	27%
Violence risk	2014	28%	72%	16%
	2015	29%	71%	20%
Sexual risk to others	2014	63%	37%	7%
	2015	65%	35%	8%
Sexual risk to self	2014	75%	25%	3%
	2015	78%	22%	3%
Fire risk	2014	86%	14%	2%
	2015	86%	14%	2%
Self-injury risk	2014	51%	49%	6%
	2015	52%	48%	7%
Property risk	2014	52%	48%	6%
	2015	52%	48%	6%

Data Source: Learning Disability Census 2015. Reference data table 5

Base: All patients (3,230 in 2014 and 3,000 in 2015)

Suppression rules: * represents a figure less than 5 that has been suppressed. See 'Introduction' for information on suppression rules. Due to suppression, figures may not sum.

Note: Figures for 'present' aggregated 'present only' and 'severe enough to require hospital treatment' at source, these were rounded for this table. Reference data table 5 shows un-aggregated data, due to rounding; summing the reference data table figures may give slightly different results.

Figure 8 shows the proportion of patients by the number of risks (severe enough to require hospital treatment) they were recorded as having. On census day in 2015, 2,195 patients (73%) were not recorded as having any risks that were severe enough to require hospital treatment, whilst 455 patients (15%) had one risk only. This shows that for most patients, there were no single risks recorded as severe enough to require hospital treatment. However the cumulative effect of several lesser risks could have an impact on overall assessment but cannot be determined from this data.

2014 76% 14% ■ No severe risks 1 severe risk 2 severe risks ■3 severe risks 4 or more severe risks 2015 73% 15% 7% 50% 60% 0% 10% 20% 30% 40% 70% 80% 90% 100%

Figure 8: Percentage of patients with no, or 1 or more behavioural risks recorded as severe enough to require treatment on census day 2014 and 2015

Data Source: Learning Disability Census 2015. Reference data table 5

Base: All patients (3,230 in 2014, 3,000 in 2015)

Suppression rules: * represents a figure less than 5 that has been suppressed. See 'Introduction' for

information on suppression rules. Due to suppression, figures may not sum.

Note: This question was not asked in 2013

Behavioural risks by gender

Reference data table 19 shows the behavioural risks by various measures. Looking at gender, the data suggests that in general, both genders had a similar recorded level of risk except for sexual behaviour constituting a risk to others and injury to self. When considering risks that are both severe enough to require treatment and present only, these differences can clearly be seen:

- Sexual behaviour constituting a risks to others; 945 males (42%) presented a risk, compared to 120 females (16%);
- Self-injury; here females were more at risk. 955 males (42%) presented a risk of self-injury compared to 490 females (66%).

Behavioural risks by Mental Health Act

Reference data table 19 shows behavioural risks by the use of the Mental Health Act (MHA). For patients detained under MHA Part II, 77% (1,055 patients) were at risk of violence or threats of violence to others and for patients under MHA Part III with no restrictions, 76% (305 patients) were at risk of violence or threats of violence to others. 73% of patients with 'Other' MHA status (60 patients) had a risk of violence or threats of violence to others. As this group is small, the data are more sensitive to small changes so the results are less robust. For all behavioural risk groups, those receiving care informally had lower than average behavioural risks for each risk group.

Behavioural risks by main treatment reason

Reference data table 19 also shows behavioural risks by main treatment reason. 82% (565 patients) receiving care under a 'continuing behavioural treatment program' were recorded as being of risk of violence or threats of violence to others. For patients whose 'Current behaviour assessed as too risky for Ministry of Justice to agree any reduction in security level' at the time of the census, 54% (265) were recorded as having 'Sexual behaviour constituting a risk to others', this is the highest in this risk category (compared to all patients where 35% were recorded as having this risk).

Experience of care

Reference data tables: 4, 6, 7, 18, 19, 20, 21

This section aims to capture some of the experiences the patient may have while in inpatient care. This section provides analysis on the results of questions:

- Q24-28. The number of incidents (Self-harm, accidents, physical assault, hands on restraint, seclusion) recorded in the three months prior to census day;
- Q40a. The use of antipsychotic medication in the 28 days prior to census day;
- Q40b. Why antipsychotic medication was used;
- Q41. The use of rapid tranquilisation medication in the 28 days prior to census day;
- Q13. Treatment without consent by Second Opinion Approved Doctor.

Incidents

Questions on incidents experienced were asked in all three census collections⁴⁰. The five different incident types can be grouped together to add more clarity. These groupings are:

- Adverse experiences (accidents, physical assault and self-harm)
- Restrictive measures (hands on restraint and seclusion),

Table 8 shows that on census day 2015, 1,330 patients (44%) did not have any incidents in the three months prior to census day.

Considering each incident type in isolation; Table 8 shows that except for 'accidents', for all adverse experiences there was an observed decrease in the percentage of patients who experienced one or more incident (of that type) in the three months prior to census day. Conversely table 8 shows that for all restrictive measures there was fluctuation in the three years of data in the percentage of patients who experience one or more incident (of that type) in the three months prior to census day.

⁴⁰ . The 2013 Learning Disability Census asked for the number of incidents within a range, whereas the 2014 and 2015 Learning Disability Census asked for the actual number of incidents. Here the 2014 and 2015 census data has been aggregated up to the 2013 ranges to simplify comparisons

Table 8: Number and percentage of patients recorded as having none or one or more incident per type in the three months prior to census day 2013, 2014 and 2015

	Number			Percent		
	2013	2014	2015	2013	2014	201
otal	3,250	3,230	3,000	100%	100%	100%
No incidents recorded	1,377	1,450	1,330	42%	45%	44%
Adverse Experiences						
of which:						
Self harm						
No times	2,379	2,440	2,265	73%	75%	769
1 or more times	841	790	735	26%	25%	249
Unknown	30	-	-	1%	-	
Accidents						
No times	2,522	2,635	2,470	78%	82%	829
1 or more times	683	595	530	21%	18%	189
Unknown	45	-	-	1%	-	
Physical assault						
No times	2,499	2,485	2,335	77%	77%	789
1 or more times	720	745	665	22%	23%	229
Unknown	31	-	-	1%	-	
Restrictive Measures						
of which:						
Hands on restraint						
No times	2,089	2,150	1,970	64%	67%	669
1 or more times	1,110	1,080	1,030	34%	33%	349
Unknown	51	-	-	2%	-	
Seclusion						
No times	2,838	2,880	2,620	87%	89%	879
1 or more times	370	350	380	11%	11%	139
Unknown	42	-	-	1%	-	

Data Source: Learning Disability Census 2015. Reference data table 6 Base: All patients (3,250 in 2013, 3,230 in 2014, and 3,000 in 2015)

Suppression rules: * represents a figure less than 5 that has been suppressed. See 'Introduction' for

information on suppression rules. Due to suppression, figures may not sum.

Incidents by gender

Table 9 shows that during the three months prior to census day 2015, 69% of females (515) experienced at least one incident compared to 51% of males (1,155). Females were more likely than males to experience both an adverse experience and a restrictive measure (290 females (39%) with 485 men (22%)). Males were marginally more likely to experience just a restrictive measure whilst females were marginally more likely to experience just an adverse experience.

Table 9: Number and percentage of patients by gender with at least one incident grouped into adverse experiences and/or restrictive measures three months prior to census day 2015

		Number			Percent		
	Total	Male	Female	Male	Female		
otal	3,000	2,255	740	100%	100%		
No incidents	1,330	1,100	225	49%	31%		
At least one incident of which:	1,670	1,155	515	51%	69%		
Adverse experiences only	600	435	170	19%	23%		
Restrictive measures only	295	240	55	11%	7%		
Incidents of both type	775	485	290	22%	39%		

Data Source: Learning Disability Census 2015. Reference data table 20

Base: All patients (3,000 in 2015)

Suppression rules: * represents a figure less than 5 that has been suppressed. See 'Introduction' for information on suppression rules. Due to suppression, figures may not sum.

Note: 'At least one incident' is shown here rounded from raw data. This can be calculated from the reference data table 20 but due to suppression totals may not add up.

Note: Figures for Gender 'Not specified' have not been included in this table due to small numbers therefore totals may not add up.

Incidents by ward gender type

Figure 9 shows the occurrence of incident by incident group and by the gender designation of the ward^{41,42}. Overall, the number of patients experiencing at least one incident during the three months prior to data collection remained largely the same between the three census collections.

Results from all three census collections suggest that females receiving care on a femaleonly ward were more likely to experience at least one incident than females on a mixed ward. In the three months prior to census day 2015, 115 females on a mixed ward (41%) did not experience any incidents compared with 110 females who were on a female-only ward (24%).

⁴¹ In the 2014 Learning Disability Census, there were 20 patients who were recorded as being on the wrong gender ward; these have been removed from this analysis. In the 2013 Learning Disability Census collection there were 15 patients recorded on the wrong gender ward who were also removed from this analysis. In 2015 a new validation was created to ensure that male patients were not coded as being on female only wards and vice versa.

⁴² Age and gender information for the 2013 census collection has been updated following a tracing exercise through the HSCIC Personal Demographics Service (PDS). Numbers for 2013 published here may differ from those published in the 2013 Learning Disability Census report. See 'data presentation' section.

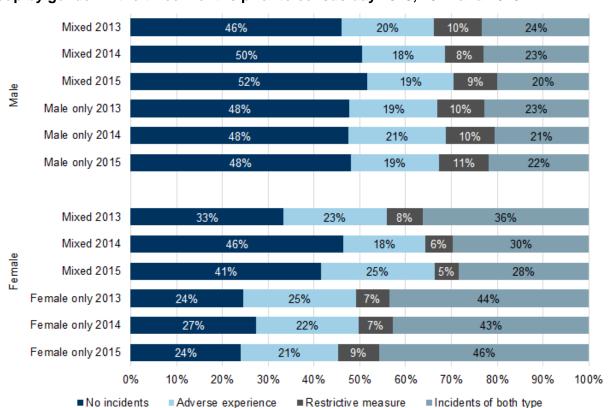


Figure 9: Percentage of patients by gender that experienced one or more incident per incident group by gender in the three months prior to census day 2013, 2014 and 2015

Data Source: Learning Disability Census 2015. Reference data table 20

Base: 3,235 in 2013, 3,210 in 2014, and 3,000 in 2015

Suppression rules: * represents a figure less than 5 that has been suppressed. See 'Introduction' for information on suppression rules. Due to suppression, figures may not sum.

Note: Some patient's had an incorrect ward gender coding in 2013 and 2014 (for example a male patient in a female only ward) these have been removed.

Note: The gender question had a new option in 2015 of 'Not known' this and the category 'not specified' are not shown here due to small numbers.

Note: The Learning Disability Census 2013 question for incidents gave an option 'unknown' for each individual incident category. When grouping to the groups shown above, unknown were assumed to be 'no incidents'. Data for 2013 includes updated information for age and gender since publication of the 2013 Learning Disability Census so figures may differ from those previously published. See 'data presentation' Data for age and gender for 2013 has been revised since the initial publication therefore information presented here will not match previously published data.

Incidents by main treatment reason

Reference data table 20 shows grouped incidents by the 'main treatment reason'. Patients recorded as being on a 'behavioural treatment programme' experienced the highest number of incidents in the three months prior to census day 2015⁴³. Only 31% of patients (210) did not experience at least once incident of some kind. The group 'Other' experienced the least incidents and 64% of patients (180) did not experience any incidents in the three months prior to census day.

⁴³ Patients in the group 'residential care placement funding dispute' experienced the least incidents, however there were only 10 patients in this group so the figures are not very robust.

Medication

Questions on the use of medication were asked in all census collections. This is in relation to antipsychotic medication, and why it is used. There is one question on the use of rapid tranquilisation.

Antipsychotic drug use

According to NICE guidance⁴⁴, antipsychotic medications are used to treat symptoms of psychosis such as hearing voices and seeing things that are not real. The use of antipsychotic medication was explored in some detail in Learning Disability Census 2013 further analysis report⁴⁵. It is noteworthy that despite initiatives to address the use of medication as found in Positive and Proactive Care: reducing the need for restrictive measures as a means of restraint⁴⁶, the use of such medication has only dropped slightly since the 2014 census and is still not back to the level reported on census day 2013.

The use of antipsychotic medication was further recognised by NHS England⁴⁷ in July 2014 where it stated: "NHS England has today promised rapid and sustained action to tackle the over-prescribing of psychotropic drugs to people with learning disabilities after three separate reports highlighted the need for change".

Table 10 displays the use of antipsychotic medication in the 28 days prior to census day. Responses available were: none, regular usage only, PRN usage only ('Pro Re Nata' meaning as and when needed) or regular and PRN use. In 2015 2,155 patients (72%) received antipsychotic medication either regularly or PRN in the 28 days prior to census, this compares to 73% in 2014 and 68% in 2013.

Table 10: Number and percentage of patients by use of antipsychotic medication in the 28 days prior to census day 2013, 2014 and 2015

		Number			Percent		
	2013	2014	2015	2013	2014	201	
Total	3,250	3,230	3,000	100%	100%	100%	
None	1,030	885	840	32%	27%	28%	
Yes	2,220	2,345	2,155	68%	73%	72%	
of which:							
Regularly	1,316	1,680	1,570	40%	52%	52%	
PRN	156	150	135	5%	5%	5%	
Both Regularly and PRN	748	515	455	23%	16%	15%	

Data Source: Learning Disability Census 2015. Reference data table 7 Base: All patients (3,250 in 2013, 3,230 in 2014 and 3,000 in 2015)

Suppression rules: * represents a figure less than 5 that has been suppressed. See 'Introduction' for information on suppression rules. Due to suppression, figures may not sum.

⁴⁴ http://www.nice.org.uk/guidance/cg178/ifp/chapter/antipsychotic-medication

⁴⁵ http://www.hscic.gov.uk/catalogue/PUB14046

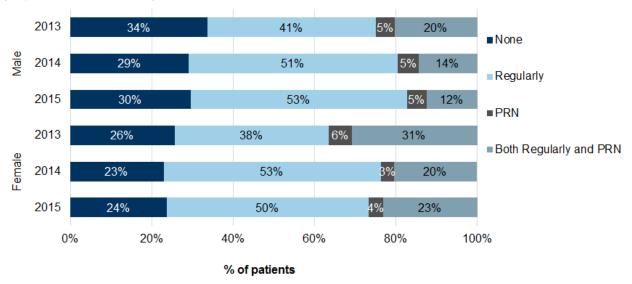
⁴⁶ https://www.gov.uk/government/uploads/system/uploads/attachment_data/file/300293/JRA_DoH_Guidance_o n_RP_web_accessible.pdf

https://www.england.nhs.uk/2015/07/14/urgent-pledge/

Antipsychotic drug use and gender

Figure 10 shows the use of antipsychotic drugs by gender. For both genders, the use of antipsychotic medication has remained largely static since the 2014 census collection reflecting the overall pattern of antipsychotic usage between the two collections. However, females still experience more usage of antipsychotic medication than males.

Figure 10: Percentage of patients by gender and use of antipsychotic medication in the 28 days prior to census day 2013, 2014 and 2015



Data Source: Learning Disability Census 2015. Reference data table 21 Base: All patients (3,250 in 2013, 3,230 in 2014, and 3,000 in 2015)

Suppression rules: * represents a figure less than 5 that has been suppressed. See 'Introduction' for

information on suppression rules. Due to suppression, figures may not sum.

Note: 2013 data includes updated information for age and gender since publication of the 2013 Learning

Disability Census so figures may differ from those previously published. See 'data presentation'

Antipsychotic drug use and diagnosis

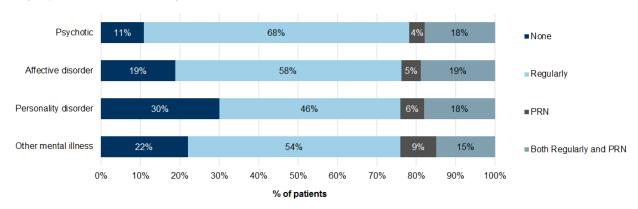
Figure 11 compares antipsychotic drug use by diagnosis. The diagnoses of learning disabilities and autism have not been included in this analysis as they should not be a reason for receiving medication.

The chart shows that 89% of patients with a psychotic disorder (765 patients) received some form of antipsychotic medication within the 28 days prior to census day. A diagnosis of 'affective disorder' is also associated with a higher level of medication; of those with this diagnosis, 81% of patients (385 patients) received some form of antipsychotic medication.

This is, to some extent, to be expected since antipsychotic drugs are indicated for treatment of psychotic disorders, aggression associated with autism in children and the management of acute behavioural disturbance⁴⁸.

⁴⁸ Brief details describing typical and atypical antipsychotic medication is available from: http://www.rcpsych.ac.uk/healthadvice/treatmentswellbeing/antipsychoticmedication.aspx

Figure 11: Percentage of patients by diagnostic category and use of antipsychotic medication 28 days prior to census day 2015



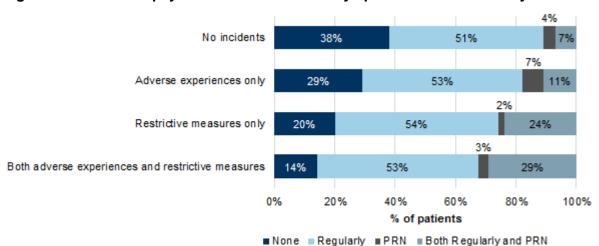
Base: All patients (2,790 who had a diagnostic category on census day of either psychotic, affective disorder or other mental illness)

Suppression rules: * represents a figure less than 5 that has been suppressed. See 'Introduction' for information on suppression rules. Due to suppression, figures may not sum.

Antipsychotic drug use and incidents

Figure 12 shows the use of antipsychotic medication by incident group. The chart suggests that having an incident of any kind increased the likelihood of a patient receiving some form of antipsychotic medication. The use of 'Regular and PRN' medication was more common in those who experienced either a 'restrictive measure only' or 'both restrictive measures and adverse experiences'; 70 patients (24%); and 225 patients (29%) respectively.

Figure 12: Use of antipsychotic medication 28 days prior to census 2015 by incidents groups



Data Source: Learning Disability Census 2015. Reference data table 21

Base: All patients (3,000 in 2015)

Suppression rules: * represents a figure less than 5 that has been suppressed. See 'Introduction' for information on suppression rules. Due to suppression, figures may not sum.

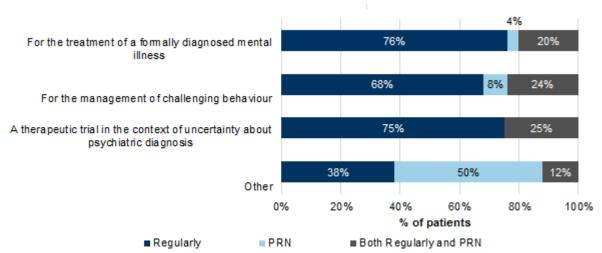
Antipsychotic drug use and reason for administration

The 2014 census asked a new question about why antipsychotic medication was administered. This question was included again in 2015. This was answered on behalf of 2,155 patients. Reference data table 7 showed that overall, 1,420 patients (66%) received antipsychotic medication for treating a formally diagnosed mental illness, and 645 patients (30%) received this for the management of challenging behaviour. 25 (1%) patients received

this for a therapeutic trial in the context of uncertainty about psychiatric diagnosis and the remaining 70 patients (3%) received this for an 'Other' reason. The number of patients receiving antipsychotic medication for the management of challenging behaviour has decreased by 10% from 2014 (715 patients in 2014 to 645 patients in 2015).

Figure 13 looks at why this medication was used by method of administration. For all reasons (except 'Other' reason) for administering antipsychotic medication, 'Regular' was the predominant method of administration with over 68% of patients receiving antipsychotic medication this way for each reason. The 'other' category showed a much greater usage of PRN only with 35 patients (50%) receiving medication in this way.

Figure 13: Reasons for the use of antipsychotic medication 28 days prior to census day 2015 by method of administration



Data Source: Learning Disability Census 2015. Reference data table 21

Base: All patients who received antipsychotic medication (2,155 in 2015) Suppression rules: * represents a figure less than 5 that has been suppressed. See 'Introduction' for

information on suppression rules. Due to suppression, figures may not sum.

Rapid tranquilisation usage

According to NICE Guidance⁴⁹ rapid tranquilisation is 'when medicines are given to a person who is very agitated or displaying aggressive behaviour to help quickly calm them'. This is done in order to reduce any risk to the patient or others, and allow them to receive the medical care that they need.

Reference data table 7 shows that 320 patients (11%) in 2015 had received this medication at some point in the 28 days prior to census day.

Rapid tranquilisation and antipsychotic medication usage

Looking at the use of both types of medication together, figure 14 suggests that if a patient was receiving antipsychotic medication regularly, particularly on a 'Both Regular and PRN' basis, then that person was more likely to also receive rapid tranquilisation. 135 patients (30%) patients who were in receipt of both regular and PRN antipsychotic medication received rapid tranquilisation compared to 30 patients (4%) of those who received no antipsychotic medication.

⁴⁹ http://www.nice.org.uk/advice/esuom28/ifp/chapter/what-is-rapid-tranquillisation

Medication usage 96% None Regularly 91% 9% PRN 91% 9% Both Regularly and PRN 70% 30% 0% 20% 40% 60% 80% 100% % of patients ■Use of rapid Tranquilisation - No Use of rapid Tranquilisation -Yes

Figure 14: Use of rapid tranquilisation and antipsychotic medication in the 28 days prior to census day 2015

Base: All patients (3,000 in 2015)

Suppression rules: * represents a figure less than 5 that has been suppressed. See 'Introduction' for information on suppression rules. Due to suppression, figures may not sum.

Rapid tranquilisation and incidents

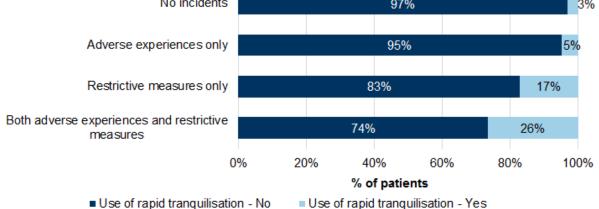
Figure 15 shows the use of rapid tranquilisation 28 days prior to census day by whether a patient had had any incidents (classified as adverse experiences, restrictive measures or both) in the three months prior to census day. The chart shows that those with no incidents are least likely to experience rapid tranquilisation, 35 patients (3%) of those with no incidents received rapid tranquilisation. Of the 775 patients who experienced both at least one adverse experience and at least one restrictive measure, 200 patients (26%) received rapid tranquilisation.

Figure 15: Use of rapid tranquilisation 28 days prior to census day by incidents groups three months prior to census day 2014

No incidents

97%

3%



Data Source: Learning Disability Census 2015. Reference data table 21

Base: All patients (3,000 in 2015)

Suppression rules: * represents a figure less than 5 that has been suppressed. See 'Introduction' for information on suppression rules. Due to suppression, figures may not sum.

Treatment without consent by Second Opinion Approved Doctor (SOAD)

If a detained patient is receiving medication for the treatment of mental disorder and more than 3 months has elapsed since they were first given such medication as a detained patient, then section 58 of the Mental Health Act requires that either the Approved Clinician in charge of the treatment (if the patient has capacity and is consenting to the treatment) or an independent doctor (if the patient lacks capacity or has capacity but is refusing) must certify that the patient should continue to receive the medication or it must be stopped. The independent doctor is selected by the Care Quality Commission (CQC) and is called a Second Opinion Appointed Doctor (SOAD).

Reference data table 4 shows there is little change in the proportion of inpatients receiving treatment authorised without their consent by a SOAD under section 58 of the Mental Health Act. 38% in 2013 and 40% in both 2014 and 2015 (relating to 1,190 patients in 2015)

Use of independent advocacy

Reference data tables: 8, 22

This section provides analysis on the results of questions:

- Q45a. Use of independent advocacy in the last 12 months;
- Q45b-f. Types of advocate used;
- Q45g. If an advocate was not used, why not.

An independent advocate is someone who can help a person with learning difficulties to get their views heard and also to help them make choices about the care they are given.

There was little change between 2014 and 2015⁵⁰ on the use of independent advocates. On census day in 2015, 2,170 patients (72%) were making use of an independent advocate compared to 2,320 patients (72%) on census day 2014.

The different types of independent advocate available are:

- Family member;
- Independent person;
- IMCA (Independent Mental Capacity Advocate);
- IMHA (Independent Mental Health Advocate);
- Non-instructed Advocate.

A patient can have more than one advocate. Figure 16 shows that on census day in 2015 IMHA was the most common type of advocate used with 1,525 patients (51%) making use of this type. The use of a family member as an independent advocate has dropped from 1,070 patients (33%) on census day 2014 to 785 patients (26%) on census day 2015.

⁵⁰ This question was not asked in 2013

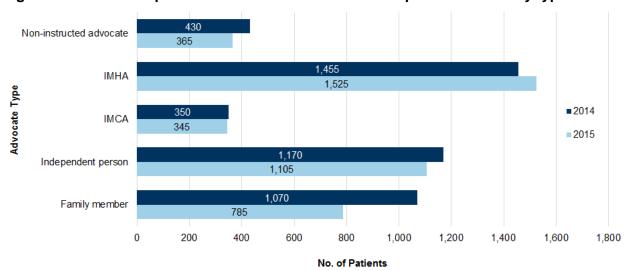


Figure 16: Number of patients who make use of each independent advocacy type

Base: All patients (3,230 in 2014, 3,000 in 2015)

Suppression rules: * represents a figure less than 5 that has been suppressed. See 'Introduction' for

information on suppression rules. Due to suppression, figures may not sum.

Note: This question was not asked in 2013

Use of an advocate and treatment without consent by Second Opinion Approved Doctor (SOAD)

Patients receiving treatment without consent by Second Opinion Approved Doctor (SOAD) are likely to be vulnerable; as such the use of an independent advocate would help to represent their views. Reference data table 22 shows there were 1,190 patients receiving treatment without consent, of whom 950 (80%) made use of an independent advocate, 200 patients (17%) chose not to use an advocate and for 40, the usage was not known (3%)

Care plan and discharge status

Reference data table: 9, 10, 23

This section provides analysis on the results of questions:

- Q44c. Discharge status as per the care plan;
- Q44a. Care plan agreement with the commissioner;
- Q44b. Care plan agreement with the relevant community clinical team;
- Q44d,e. Reasons for delays and who attributed to;
- Q44f. Review discussions;
- Q44q. Family involvement in discussing the care plan.

The care plan is where details of patients' projected transfer dates are stored, along with other key information for each individual based around their and their families' needs and agreed outcomes. The DH Winterbourne View Review Concordat: Programme of Action⁵¹ identified care planning as important stating:

⁵¹ https://www.gov.uk/government/uploads/system/uploads/attachment_data/file/213217/Concordat.pdf

- "By 1 June 2013, working together and with service providers, people who use services and families review the care of all people in learning disability or autism inpatient beds and agree a personal care plan for each individual, based on their and their families' needs and agreed outcomes;
- Put these plans into action as soon as possible, so that all individuals receive personalised care and support in appropriate community settings no later than 1 June 2014:
- Ensure that all individuals have the information, advice and advocacy support they
 need to understand and have the opportunity to express their views. This support will
 include self-advocacy and independent advocacy where appropriate for the person
 and their family."

Building the right support⁵² published in October 2015 further reinforced that care planning was a core element of the national service model:

"Care and support should be person-centred, planned, proactive and coordinated – with early intervention and preventative support based on sophisticated risk stratification of the local population, person-centred care and support plans, and local care and support navigators/keyworkers to coordinate services set out in the care and support plan."

Details of the care plan

Table 11 displays the details of each patients care plan and discharge status. The proportion of inpatients who need inpatient care according to the care plan has risen slightly for each census collection from 66% in 2013, to 67% in 2014 and 68% in 2015.

Considering the results from census day 2015 in more detail; 805 patients (27%) were reported to have a care plan record of 'working towards discharge' whilst 145 patients (5%) are recorded as having a delayed transfer due to placement unavailability. This leaves a total 2,050 patients (68%) whose care plan status identifies that the patient needs to remain in inpatient care.

In comparison with 2013 and 2014 census results, the proportion of patients who were not ready for transfer as per the care plan was similar each year (66% in 2013 compared with 67% in 2014 and 68% in 2015). There has been no considerable change in the recorded reasons however when compared with 2014 data. Table 11 shows the data for each year.

-

⁵² https://www.england.nhs.uk/wp-content/uploads/2015/10/ld-nat-imp-plan-oct15.pdf

Table 11: Details of patients care plan on census day 2013, 2014 and 2015

				% difference between
	2013	2014	2015	2014 & 2015
Total	3,250	3,230	3,000	-7%
Need inpatient care according to care plan Of which:	2,145	2,175	2,050	-6%
Currently not dischargeable because of level of behaviour that presents a risk to the person or others, or mental illness	496	895	850	-5%
Currently receiving active treatment plan, discharge plan not in place	1,508	1,185	1,120	-6%
Requires indefinite IP care because of behavioural needs	115	75	50	-36%
Requires indefinite IP care because of physical needs	26	20	30	60%
Do not need inpatient care according to care plan Of which:	1,105	1,055	950	-10%
Working towards discharge to identified placement or with discharge plan in place	953	900	805	-11%
No onward placement available, delayed transfer of care	152	155	145	-7%

Base: All patients (3,250 in 2013, 3,230 in 2014, and 3,000 in 2015)

Suppression rules: * represents a figure less than 5 that has been suppressed. See 'Introduction' for information on suppression rules. Due to suppression, figures may not sum.

Note: Reference to 'risk' was not included in the 2013 option 'Currently not dischargeable because of level of behaviour that presents a risk to the person or others, or mental illness'.

For the 145 patients who were recorded as having a delayed discharge, further questions were asked as to what the reason for delay was. Delayed discharge indicates that a clinician has deemed the patient is ready to re-enter to a community setting or transfer to another inpatient setting but that a place is not yet available.

Table 12 shows that 41% of delays were attributed to waiting for residential home availability, and 4% were awaiting nursing home availability. The first seven options for this question were regarding resources, and these accounted for 94% of responses. These figures are in line with the results from the 2014 census when the question was first asked.

Table 12: Reasons for delayed discharge on census day 2015

	Number	Percent
Total delayed discharges	145	100%
Awaiting completion of assessment	20	14%
Awaiting public funding	10	8%
Awaiting further non-acute NHS care	30	20%
Awaiting residential home placement or availability	60	41%
Awaiting nursing home placement or availability	5	4%
Awaiting care package in own home	10	6%
Awaiting community equipment and adaptations	*	*
Patient or family choice	5	3%
Disputes	*	*
Housing - Patient not covered by NHS and Community Care Act	*	*

Base: All patients with delayed discharge (145 in 2015)

Suppression rules: * represents a figure less than 5 that has been suppressed. See 'Introduction' for information on suppression rules. Due to suppression, figures may not sum.

It is worth noting that in Winterbourne View – Time for Change⁵³, Sir Stephen Bubb stated "We must see a step change …. putting in place the community-based support to safely discharge people currently in inpatient settings". This is in accordance with data presented in tables 10 and 11 which shows the number of people waiting for community services to become available and being delayed by systemic issues. These issues are to be addressed through the national service model. ⁵⁴

Question 47 asked about the actual weekly cost of the patient's placement (this is fully covered in the 'Costs' section below). The average weekly cost per patient for the 145 patients recorded as having a 'delayed transfer' was £3,771 as shown in reference data table 23. The approximate weekly cost for these patients was £546,795.

Table 13 shows which organisation type the delay was attributed to. In 32% of cases the delays were primarily attributed to health care delays by the NHS, in 34% of cases, the delays were primarily attributed to social care, and in 23% of cases both agencies were considered to share the responsibility.

44

⁵³ http://www.england.nh<u>s.uk/wp-content/uploads/2014/11/transforming-commissioning-services.pdf</u>

https://www.england.nhs.uk/wp-content/uploads/2015/10/ld-nat-imp-plan-oct15.pdf

Table 13: Which organisation is primarily responsible for the patients recorded in the care plan as delayed discharge on census day 2015

	Number	Percent
Total delayed discharges	145	100%
NHS (local commissioner)	25	16%
NHS (specialist commissioner)	10	6%
NHS (local provider)	15	10%
Social Care	50	34%
Both health and social care agencies	35	23%
Ministry of Justice	*	*
Other	15	10%

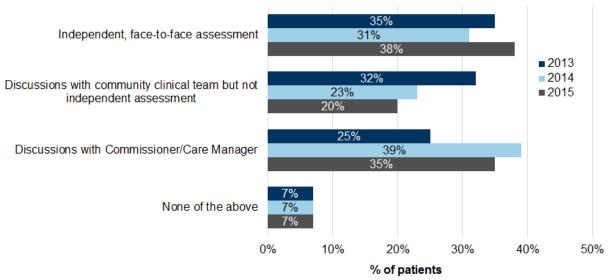
Base: All patients with delayed discharge (145 in 2015)

Suppression rules: * represents a figure less than 5 that has been suppressed. See 'Introduction' for information on suppression rules. Due to suppression, figures may not sum.

Care plan discussions

Figure 17 shows discussions on care plans that have taken place in the last year. Only one option was available per patient. The figures suggest an increase in independent face to face assessments; 1,150 (38%) in 2015 received this compared with 1,000 patients (31%) in 2014. For 'discussion only' assessments, the 2015 census collection showed there was a decrease in discussions with only the commissioner/care manager (35% in 2015 from 39% in 2014) and a decrease in discussions with the clinical teams (20% in 2015 from 23% in 2014).

Figure 17: Percentage of patients by discussions held within the last year on census day 2013, 2014 and 2015



Data Source: Learning Disability Census 2015. Reference data table 10

Base: All patients (3,250 in 2013, 3,230 in 2014, and 3,000 in 2015)

Suppression rules: * represents a figure less than 5 that has been suppressed. See 'Introduction' for information on suppression rules. Due to suppression, figures may not sum.

Care plan agreements

Reference data table 10 shows care plan agreements with the commissioner and community clinical team. On census day 2015, 2,775 patients (93%) had their care plan agreed with the commissioner, 2,630 patients (88%) had their care plan agreed with the community clinical team and 2,530 patients (84%) had their care plan agreed with both the commissioner and the community clinical team.

The percentage of people who had care plan agreements with both commissioner and community clinical team increased from 80% representing 2,600 patients in 2014 to 84% representing 2,530 patients in 2015.

Family involvement

Having family involvement in discussions can help to ensure all the patients' needs are being addressed and considered. Reference data table 9 shows that 2,085 patients (70%) had family involved their care plan discussion. This is the same proportion as for 2014.

Length of stay and distance from home⁵⁵

Reference data tables: 11, 24, 25, 26

This section provides analysis on the results of questions:

- Q16a. Date of admission to current hospital spell with this provider
- Q16b. Date of first admission to any hospital as part of this continuous period of inpatient care
- Q9c. Postcode of last known residential address of patient before admission to hospital
- Q10. Postcode of next of kin
- Q35. Postcode of the hospital where the patient is receiving treatment

The measures of length of stay and distance from home are important as they can provide indication as to appropriateness of current placement. Transforming Care⁵⁶ noted that people requiring inpatient services should be treated locally wherever possible, as sending people out of their local area can weaken their existing relationships with family and friends, damage continuity of care, and result in people being placed in settings that are unfamiliar and stressful.

Information on the home address of the patient and the home address of the next of kin was collected and was used to calculate the distance from the ward to home. The Background Methodology and Data Quality Report explains the calculations made.

⁵⁵ The reference data tables use smaller time bands and distances than used in some sections of this report, some groups have been aggregated to provide more meaningful results. Due to rounding, summing information in the reference data tables may yield slightly different figures.

⁵⁶ Department of Health, "Transforming care; a national response to Winterbourne View Hospital" (Department of Health, 2013), https://www.gov.uk/government/uploads/system/uploads/attachment_data/file/213215/final-report.pdf

Length of stay⁵⁷

Length of stay is calculated as the difference between admission date and census day. Both the mean and median length of stay was calculated, plus the number of patients within each time band are shown in Figure 18.

2013: Mean length of stay: 1,065 days

Median length of stay: 542 days

2014: Mean length of stay: 1,034 days

Median length of stay: 547 days

Median length of stay: 554 days

It is worth reiterating that the 2015 Learning Disability Census identified 245 patients who could have been included in the 2014 Learning Disability Census (according to first admission date recorded in 2015 for the same patient) as all 245 patients had a total length of stay greater than a year on census day in 2015. 295 patients⁵⁸ could also have been included in the 2013 Learning Disability Census as these patients had a total length of stay greater than two years on census day 2015.

Reference data tables 24, 25 and 26 provide cross tabular information on length of stay by various measures.

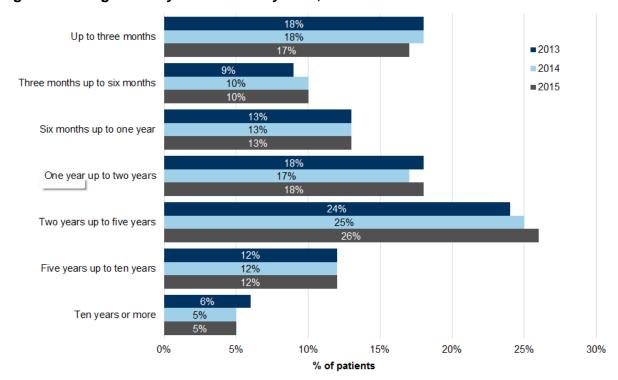


Figure 18: Length of stay on census day 2013, 2014 and 2015

Data Source: Learning Disability Census 2015. Reference data table 11 Base: All patients (3,250 in 2013, 3,230 in 2014, and 3,000 in 2015)

Suppression rules: * represents a figure less than 5 that has been suppressed. See 'Introduction' for information on suppression rules. Due to suppression, figures may not sum.

Copyright © 2015, Health and Social Care Information Centre. All rights reserved.

47

⁵⁷ The reference data tables use smaller time bands than presented in this section. Due to rounding, summing information in the reference data tables may yield different figures.

⁵⁸ Note that the 245 patients and 295 patients are not necessarily connected (for example some of the 295 unreported in the 2013 census may appear in the 2014 census).

Length of stay by age and gender

Reference data table 24 shows that males had a much higher chance of a longer hospital stay than females as was the case in 2014 and 2013. On census day in 2015, 1,420 men (63%) had a length of stay of one year or more compared with 390 (53%) of women. This is comparable with the findings from the 2013 and 2014 Learning Disability Censuses. The proportion of patients with a length of stay of one year or more increased with age up to age 64; this is 21% (35 patients) of under 18s, 60% (890) of 18-34 year olds, 67% (845 patients) of 35-64 year olds and 54% (40 patients) of over 65 year olds.

Length of stay by ward security level⁵⁹

The reference data table 24 shows that, the proportion of patients with a length of stay of over one year is higher in secure wards. 48% (750 patients) on a general ward, 77% (620 patients) on a low secure ward, 72% (375 patients) on a medium secure ward and 91% (60 patients) on a high secure ward had a length of stay of more than one year. Of those in a high secure ward, 59% (40 patients) have been in these settings five years or more.

Length of stay by provider type

Figure 19 considers length of stay by provider type split by NHS and independent providers. 900 patients (67%) had a length of stay over one year for those receiving inpatient care with an independent provider compared with 910 patients (55%), of those receiving inpatient care with an NHS provider.

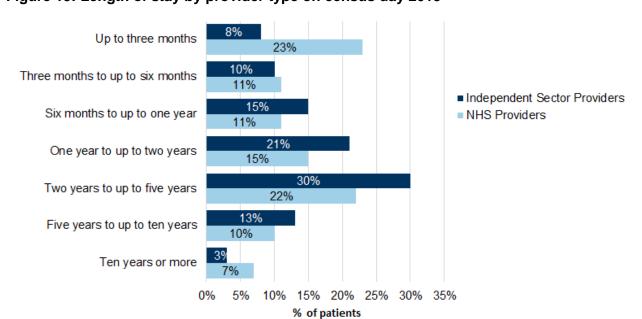


Figure 19: Length of stay by provider type on census day 2015

Data Source: Learning Disability Census 2015. Reference data table 24

Base: All patients (3,000 in 2015)

Suppression rules: * represents a figure less than 5 that has been suppressed. See 'Introduction' for

information on suppression rules. Due to suppression, figures may not sum.

⁵⁹ Figures have been calculated from the raw data and then suppressed, due to rounding, summing the figures in the reference data table may yield slightly different results.

Total length of stay

Any provider who had a patient who transferred from another hospital setting was also required to supply an answer to 'Q16b: Date of first admission to any hospital as part of this continuous period of inpatient care'. This question was repeated again in 2015. In total, 1,325 patients (44%) transferred directly from other inpatient services in the 2015 Learning Disability Census⁶⁰. Analysis for total length of stay uses the response to Q16b where supplied or Q16a⁶¹ otherwise.

Figure 20 compares length of stay with this provider with total length of stay. The chart shows that when taking into account of transfers from other hospitals, the number of patients who had been in inpatient care for over 5 years increases from 510 patients to 895 patients.

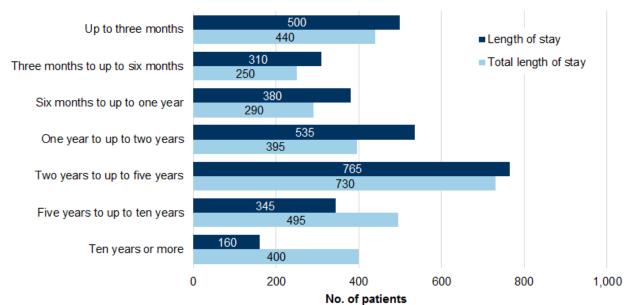


Figure 20: Total Length of stay and length of stay on census day 2015

Data Source: Learning Disability Census 2015. Reference data table 11 Base: All patients (3,000 in 2015)

Suppression rules: * represents a figure less than 5 that has been suppressed. See 'Introduction' for information on suppression rules. Due to suppression, figures may not sum.

Table 14 compares length of stay and total length of stay. The table shows that of those patients who have a length of stay of 'up to three months', for 440 patients in this group (88%) this is also their total length of stay, i.e. they have not transferred from anywhere else or if so it was within three months (or same time band). For 345 patients (65%) in the group who have a length of stay between one and two years this period is their total length of stay, the remaining 190 patients (35%) have a total length of stay which is much longer.

This shows the extent to which length of stay in the current placement (the only measure collected in 2013) understates the total length of stay does not take into account moves from other hospitals as part of this current continual period of inpatient care.

⁶⁰ Reference data table 2

⁶¹ Q16a. Date of first admission to current hospital spell with this provider

Table 14: Length of stay by total length of stay on census day 2015

	Total length of stay									
Length of stay	Total	Up to three months	Three months up to six months	Six months up to one year	One year up to two years	Two years up to five years	Five years up to ten years	Ten years or more		
Up to three months	100%	88%	3%	2%	2%	3%	2%	*		
Three months up to six months	100%	*	75%	4%	5%	7%	6%	3%		
Six months up to one year	100%	*	*	70%	7%	11%	5%	7%		
One year up to two years	100%	*	*	*	65%	19%	11%	5%		
Two years up to five years	100%	*	*	*	*	73%	15%	12%		
Five years up to ten years	100%	*	*	*	*	*	78%	22%		
Ten years or more	100%	*	*	*	*	*	*	100%		

Base: All patients (3,000 in 2015)

Suppression rules: * represents a figure less than 5 that has been suppressed. See 'Introduction' for information on suppression rules. Due to suppression, figures may not sum.

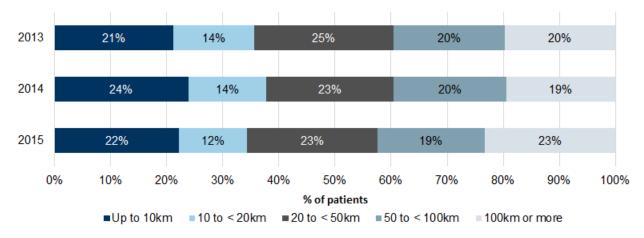
Distance from home

The mean distance from home in 2013 was 60.5km, the median was 34.5km. For 2014 the mean was 59.5km and the median was 34.4km. In 2015 the mean was 66.2km and the median was 38.6km.

The average distance along with information in Figure 21 indicates that the distance a patient is from home when on an inpatient ward has not changed much between all three census collections.

Reference data tables 24, 25 and 26 provide cross tabular information on distance from home by various measures.

Figure 21: Distance from home on census day 2013, 2014 and 2015



Data Source: Learning Disability Census 2015. Reference data table 11

Base: All patients (2,890 in 2013, 2,950 in 2014 & 2,875 in 2015)

Suppression rules: * represents a figure less than 5 that has been suppressed. See 'Introduction' for information on suppression rules. Due to suppression, figures may not sum.

Distance from home by ward security

Reference data table 26 displays distance from home by ward security. Patients in a high secure ward were more likely to be further from home; of these, 45⁶² patients (77%) were in hospital 50km or more away from their home address. However, in all of the census collections, there were patients in general wards who were also over 50km from their home address. 2015 figures show that 490 patients (33%) were placed more that 50km from their home address. There are fewer high secure wards and, due to the extra security needed to manage these wards, they tend to be larger facilities catering for more patients. Note that PICU wards were recorded within 'low secure' in 2013

Distance from next of kin

The 2014 census asked a new question regarding the postcode of the next of kin. This question was repeated again in 2015. For 38%⁶³ of patients, this was unknown. This does not necessarily indicate that the hospital does not have any contact details for the next of kin - they may have address and phone number but not postcode. Figure 22 below shows both the distance from home and the distance from next of kin. The proportions are very similar for the distance bands for both measures indicating that next of kin in most cases live a similar distance from the ward as the patient's home address.

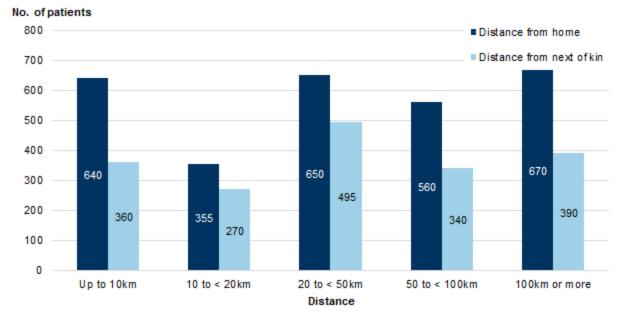


Figure 22: Distance from home and distance from next of kin on census day 2015

Data Source: Learning Disability Census 2015. Reference data table 11

Base: All patients except where home or next of kin address is same as the hospital or where distance was unknown (2,875 in 2015 for distance from home,1,855 in 2015 for distance from next of kin) Suppression rules: * represents a figure less than 5 that has been suppressed. See 'Introduction' for information on suppression rules. Due to suppression, figures may not sum.

⁶² This figure is calculated from the unsuppressed data and then rounded. Adding together suppressed data from Reference data table 26 may yield different results.

⁶³ This figure is not shown in the reference tables but can be approximated from the rounded data

Length of stay and distance from home⁶⁴

The following two charts compare the length of stay and total length of stay with distance from home. Figure 23 shows that 365 (57% of patients) staying a distance of up to 10km from home had a length of stay of up to a year. The remaining 275 patients (43%) in this distance band had a length of stay over a year.

245 (37% of patients) staying 100km or more had a length of stay of up to a year. The remaining 425 patients (63%) in this distance band have a length of stay over a year. Except for the distance banding 10-20 km, the proportion of patients who had been in inpatient care for more than one year increased as the distance increased.

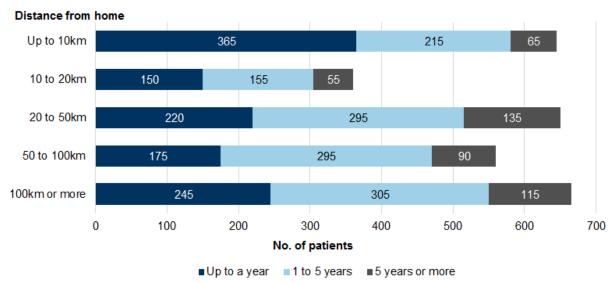


Figure 23: Length of stay and distance from home on census day 2015

Data Source: Learning Disability Census 2015. Reference data table 24

Base: All patients except where distance is the same as the hospital or unknown (2,875 in 2015) Suppression rules: * represents a figure less than 5 that has been suppressed. See 'Introduction' for information on suppression rules. Due to suppression, figures may not sum.

Note: Figures have been calculated from the raw data and then suppressed; summing the suppressed data in the reference tables may yield the same figures due to rounding.

Figure 24 shows total length of stay by distance from home⁶⁵. This mirrors the pattern seen for 'length of stay and distance from home'. Those further from home tend to have longer hospital stays.

⁶⁴ This figure is calculated from the unsuppressed data and then rounded. Adding together suppressed data from Reference data tables 24 and 25 may yield different results.

⁶⁵ Note, percentage figures cannot directly be calculated from the reference tables.

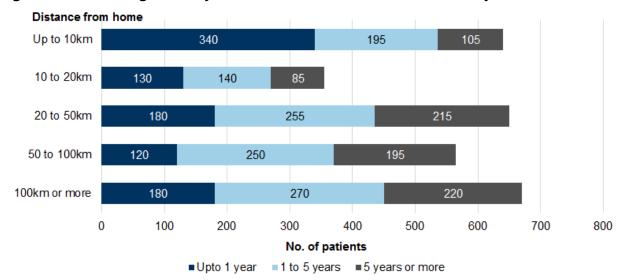


Figure 24: Total Length of stay and distance from home on census day 2015

Base: All patients except where distance is the same as the hospital or unknown (2,875 in 2015) Suppression rules: * represents a figure less than 5 that has been suppressed. See 'Introduction' for information on suppression rules. Due to suppression, figures may not sum.

Note: Figures have been calculated from the raw data and then suppressed, summing the suppressed data in the reference tables may yield the same figures due to rounding.

Geography

Reference data tables: 13, 14, 15, 28

This section provides analysis on the results of questions:

- Q9c. Postcode of last known residential address of patient prior to hospital admission;
- Q35. Postcode of the hospital where the patient is receiving treatment

The further analysis planned for release in early 2016 will analyse the data in more geographical detail by region and area team. This section provides a broad overview of the distribution of region of ward of hospital stay and region of residence for patients, and differences between the two. Reference data tables 14 & 15 display the number of patients per Clinical Commissioning Group (CCG) of residence and CCG of ward stay.

Region of hospital ward and region of residence

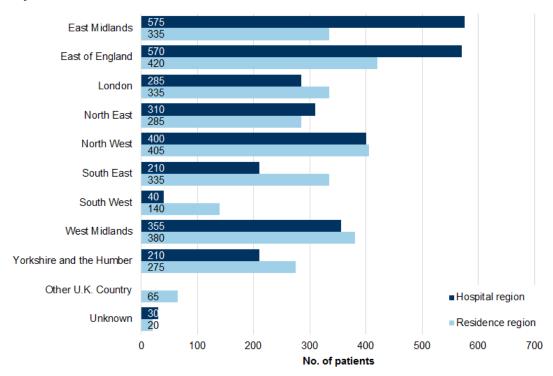
Figure 25 shows the number of patients by region of residence and region of ward stay. Differences highlight which regions 'import' patients for treatment or 'export' them for treatment. The picture for 2015 was very much the same as for 2013 and 2014; the East Midlands and East of England had more patients staying in a ward in these areas than residents who need a ward. Conversely, Yorkshire and the Humber, South West and South East both had more patients resident than staying in wards meaning that they 'exported' more patients for their care.

It is worth noting that this analysis does not consider if a patient actually received care in their region of residence. For example, if region A has capacity to treat 100 patients and region A also had 80 residents who needed inpatient care we cannot say that all 80 of the

resident received care there and the remaining 20 were 'imported' from another region. Some, or all of the 80 region A residents could have gone to region B for treatment.

The further analysis release will explore this in more detail.

Figure 25: Number of patients per region of hospital ward and region of residence on census day 2015



Data Source: Learning Disability Census 2015. Reference data table 13

Base: All patients (3,000 in 2015)

Suppression rules: * represents a figure less than 5 that has been suppressed. See 'Introduction' for information on suppression rules. Due to suppression, figures may not sum.

Note: This is an England level hospital provider collection, as such no data was provided for 'Other UK Country' hospital residence.

Comparing region of hospital ward and region of residence

Table 15 shows the proportion of patients for each hospital region and where the service user's home region is. Note that unknown postcodes and home postcodes the same as the hospital have been removed, leaving a cohort of 2,945 patients.

The colour blocks highlight those who were resident in and receiving care in the same region. The South West had the highest number of patients in hospital who were also resident in that region; 95% of the patients were receiving care in the same region (40 patients). This was closely followed by the North West where 330 of the 400 patients were receiving care in their region of residence (82%).

The East Midlands had the lowest number of patients receiving inpatient care in their region of residence at 225 of the 570 patients (40%). This is not necessarily a reflection of misaligned need and provision of care in a region and could, for instance, reflect service users needing more secure care which is not available locally. The further analysis released in early 2016 will examine this in more detail.

Table 15: Per hospital region, percentage of patients receiving inpatient care per patient region of residence on census day 2015

									Yorkshire	Other	
Hospital region	East Midlands	East of England	London	North East	North West	South East	South West	West Midlands	and the	U.K. Country	Tota
East Midlands	40%	5%	5%	3%	4%	10%	7%	11%	12%	4%	100%
East of England	7%	58%	12%	*	*	15%	3%	3%	1%	1%	100%
London	2%	8%	73%	*	*	11%	3%	*	*	*	100%
North East	2%	*	*	75%	5%	*	2%	*	10%	5%	100%
North West	2%	*	*	2%	82%	*	1%	3%	5%	2%	100%
South East	4%	6%	12%	*	*	71%	5%	*	*	*	100%
South West	*	*	*	*	*	*	95%	*	*	*	100%
West Midlands	4%	3%	*	*	7%	2%	3%	77%	*	1%	100%
Yorkshire and the Humber	12%	3%	*	3%	5%	*	*	5%	69%	*	100%

Data Source: Learning Disability Census 2015. Reference data table 28
Base: All patients except where region of residence or hospital is unknown (2,945 in 2015)
Suppression rules: * represents a figure less than 5 that has been suppressed. See 'Introduction' for information on suppression rules. Due to suppression, figures may not sum.

Table 16 shows the proportion of patients from each region receiving care in each of the regions. The data shows that on census day 2015, 230 of the 270 patients (86%) recorded as resident in the North East also received care in the North East. For the South West, only 40 of the 140 patients (29%) resident there received care in that region. Some of those who received care in different regions could still be close to home since the hospital could be just over the geographical border.

Table 16: Per patient region of residence, percentage of patients who receive care by region of hospital ward on census day 2015

					Hospital r	egion				
Residence region	East Midlands	East of England	London	North East	North West	South East	South West	West Midlands	Yorkshire and the Humber	Tota
East Midlands	68%	11%	1%	2%	3%	3%	*	4%	7%	100%
East of England	7%	79%	6%	*	*	3%	*	3%	1%	100%
London	8%	20%	63%	*	*	8%	*	*	*	100%
North East	7%	*	*	86%	3%	*	*	*	3%	100%
North West	5%	*	*	4%	82%	*	*	6%	2%	100%
South East	17%	25%	10%	*	*	44%	*	2%	*	100%
South West	28%	13%	6%	4%	4%	7%	29%	8%	*	100%
West Midlands	17%	4%	*	*	3%	*	*	71%	3%	100%
Yorkshire and the Humber	24%	3%	*	11%	8%	*	*	*	52%	100%
Other U.K. Country	35%	11%	*	26%	15%	*	*	8%	*	100%

Data Source: Learning Disability Census 2015. Reference data table 28 Base: All patients except where region of residence or hospital is unknown (2,945 in 2015) Suppression rules: * represents a figure less than 5 that has been suppressed. See 'Introduction' for information on suppression rules. Due to suppression, figures may not sum.

Costs

Reference data tables: 12, 27

This section provides analysis on the results of questions:

- Q47. Actual weekly cost of the patients placement to the nearest £100;
- Q48. Which commissioner, other organisation or individual is paying for the care.

The average weekly charge for inpatient care on census day 2015 was £3,563 per person per week. The 2014 census asked the actual weekly charge of care per patient, whist the 2013 census asked for the cost in pre-defined bandings. For comparison with 2013 census data, the 2014 and 2015 costs have been grouped into the same cost bands as used in the 2013 census.

Weekly cost by provider type

Comparing the costs by NHS and independent providers, reference data table 27 shows that on census day 2015, the average cost for inpatient care for NHS run facilities was £3,449 per patient per week. This was £3,700 for independent sector providers. Figure 26 shows the average cost per patient per week cost bands.

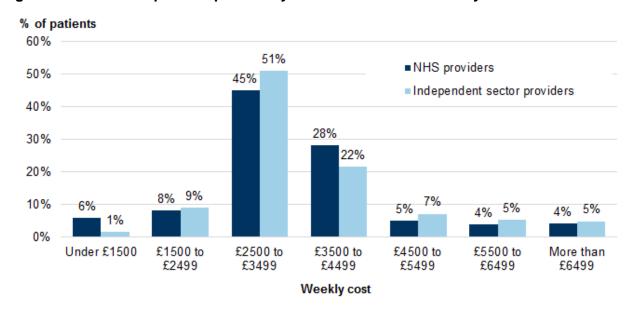


Figure 26: Number of patients per weekly cost of care on census day 2015

Data Source: Learning Disability Census 2015. Reference data table 27

Base: All patients except where cost is unknown (2,965 in 2015)

Suppression rules: * represents a figure less than 5 that has been suppressed. See 'Introduction' for information on suppression rules. Due to suppression, figures may not sum.

Weekly cost by type of organisation responsible for paying for patient care

Reference data table 12 shows which type of organisation was responsible for paying for care of the patient. CCGs paid for 1,335 patients (44%); whilst NHS England paid for 1,470 patients (49%) directly through specialist commissioned services. Local authorities paid for 80 patients (3%), a reduction of 45% (from 150) compared to 2014; and just 10 patients were paid for by a pooled budget. The remainder were paid for by either private funding, non UK commissioning, an NHS Provider or an NHS commissioner outside England.

Figure 27 uses data from reference data table 27 and compares the banded cost of care by the type of organisation paying. This shows that on average CCGs pay less than Specialist Commissioning Hubs at £3,424 per person per week compared to £3,645. 'Other NHS commissioner outside England' pays the most at £4,419 per person per week.

NHS CCG £3,424 NHS England (Specialist Commissioning) Other NHS Commisioner outside England Other NHS provider £3,354 Pooled budget £2,926 Local Authority £3,738 Private Funding Non UK Commisioning £3,400 6,000 2.000 4.000

Figure 27: Average weekly cost of inpatient care by who is paying on census day 2015

Average weekly cost per person

Data Source: Learning Disability Census 2015. Reference data table 27

Base: All patients except where cost was unknown (2,965 in 2015)

Suppression rules: * represents a figure less than 5 that has been suppressed. See 'Introduction' for information on suppression rules. Due to suppression, figures may not sum.

Copyright © 2015, Health and Social Care Information Centre. All rights reserved.

Under 18s analysis

Reference data table: 16

This section provides analysis on key questions concerning the group of patients aged under 18. This group have been separated out for analysis in this section since children need different care provisions to adults⁶⁶.

On census day in both 2013 and 2014, there were 160 patients aged under 18 (5% of both census totals). In 2015 there were 165 patients aged under 18 (6% of the total). The following sections consider the care of the 165 patients aged under 18 on census day 2015. Note, as the numbers are smaller, percentage calculations can be affected be small changes in the figures.

Main treatment reason for remaining in care for under 18s

Table 17 shows the responses for main treatment reason for remaining in care for census day 2014 and 2015⁶⁷. Overall, there was an increase in the number of patients under 18 who were in need of inpatient care for treatment reasons; 105 patients (65%) in 2014 compared to 130 patients (79%) in 2015, a 25% increase compared to 2014. On census day 2015, the main treatment reasons for remaining in care were: 'Continuing need for in-patient care of mental illness' with 75 patients (46%) having this reason; and 'Continuing behavioural treatment programme', with 55 patients (22%) having this reason.

Table 17: Main reason for remaining in inpatient care for patients under 18 years of age on census day 2014 and 2015

	Number	Number		nt
-	2014	2015	2014	201
al	160	165	100%	1009
Need inpatient care for treatment reason	105	130	65%	79
of which:				
Current behaviour assessed as too risky for Ministry of Justice to agree any reduction in security level	*	*	*	
Continuing need for inpatient care of mental illness	70	75	43%	469
Continuing behavioural treatment programme	35	55	22%	329
Oo not need inpatient care for treatment reason	25	15	17%	8
of which:				
Local step-down placement in inpatient psychiatric unit preparatory to community resettlement being actively sought	10	*	6%	
New community placement actively being sought as previous placement no longer viable	15	5	9%	49
Residential care placement funding dispute	*	*	*	
Other	30	20	18%	13

Data Source: Learning Disability Census 2015: Reference table 16

Base: All patients under 18 years old (160 in 2014, 165 in 2015)

Suppression rules: * represents a figure less than 5 that has been suppressed. See 'Introduction' for

information on suppression rules. Due to suppression, figures may not sum.

Note: This question was not asked in 2013

⁶⁶ Both the 2014 Census publication and this publication use updated ages for the 2013 census where some providers incorrectly reported the date of birth to the HSCIC. However, whilst this was noted in the 2013 report there was not sufficient time to re-analyse the data before release.

⁶⁷ This was not asked in 2013.

Incidents for under 18s

Figure 28 shows the proportions of different types of incidents for those aged under 18 in the three months prior to census day in 2013, 2014 and 2015. The proportion of patients under 18 with no incidents of any type was 33% for the 2015 census collection (55 patients) compared to 36% for the 2013 and 2014 census collections (55 and 60 patients respectively). For the whole 2015 census inpatient population, the proportion of patients with no incidents was 44%, indicating that under 18s experienced a higher proportion of incidents overall. 70 patients (41%) aged under 18 experienced both an adverse experience and a restrictive measure at some point during the three months prior to census day in 2015. For the whole 2015 census inpatient population, the proportion of patients who experienced both types of incident was 26%.

50% 45% ■2013 ■2014 ■2015 40% 35% 30% 25% 46% 41% 20% 38% 36% 33% 15% 10% 15% 15% 5% 9% 0% No incidents Incidents of both type Adverse experience Restrictive measure Incidents groups

Figure 28: Percentage of patients under 18 years of age by incident group three months prior to census day 2013, 2014 and 2015

Data Source: Learning Disability Census 2015: Reference table 16
Base: All patients under 18 years old (160 in 2013 and 2014, 165 in 2015)
Suppression rules: * represents a figure less than 5 that has been suppressed. See 'Introduction' for information on suppression rules. Due to suppression, figures may not sum.

Medication for under 18s

Figure 29 shows the use of antipsychotic medication in the 'Under 18' age group for 2013, 2014 and 2015. This shows that the overall trend for a similar use of antipsychotic medication between 2014 and 2015 as described in the section 'Experience of care' was present in those aged under 18. For this age group, the use of antipsychotic medication remained constant between the 2014 and 2015 census collections. In the 28 days prior to census day in 2014, 55 patients (36%) did not have any antipsychotic medication compared to 60 patients (36%) in 2015.

2013 31% 38% 6% 26% 2014 36% 45% 4% 16% 2015 36% 51% 13% 0% 10% 20% 30% 40% 50% 60% 70% 80% 90% 100% % of Patients ■ Regularly ■ PRN ■ Both Regularly and PRN

Figure 29: Use of antipsychotic medication for patients under 18 years of age 28 days prior to census day 2013, 2014 and 2015

Base: All patients under 18 years old (160 in 2013 and 2014, 165 in 2015)

Suppression rules: * represents a figure less than 5 that has been suppressed. See 'Introduction' for

information on suppression rules. Due to suppression, figures may not sum.

Reference data table 16 also shows the use of rapid tranquilisation in the 28 days prior to census day. In 2015 73% of under 18s (120 patients) did not receive any rapid tranquilisation compared to 79% in 2014 (125 patients). For the whole 2015 census population, the percentage who did not receive rapid tranquilisation was 89%, suggesting a higher level of rapid tranquilisation amongst the under 18s⁶⁸.

Advocacy usage for under 18s

Reference data table 16 shows that 110 patients (68%) aged under 18 made use of an independent advocate; the overall LD population figure was 72% of patients. Figure 30 shows the advocacy types used. An independent person was the most used type with 90 patients (56%) of all under 18 making use of this service. Patients can make use of more than one type of independent advocate.

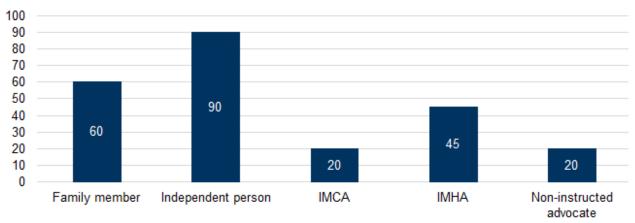
Reference data table 16 shows that 88% of patients under 18 years old have a family member involved in the discussion of their care plan. This measure is 70% for all patients indicating a higher level of family involvement for under 18s.

-

⁶⁸ This question was not asked in 2013

Figure 30: Number of patients under 18 years of age who made use of each advocacy type on census day 2015





Base: All patients under 18 years old (165 in 2015)

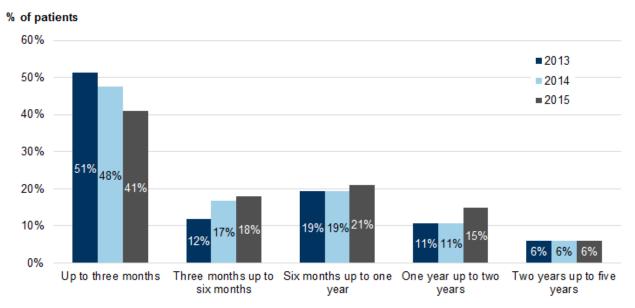
Suppression rules: * represents a figure less than 5 that has been suppressed. See 'Introduction' for information on suppression rules. Due to suppression, figures may not sum.

Length of stay for under 18s

For the under 18 population, the length of stay was generally lower than for the overall learning disability census population. 65 patients (41%) of those under 18 had a length of stay of up to three months on census day 2015; for the general census population this was 17%. Only 21% of under 18s had a length of stay of one year or more compared to 60% of the 2015 census population. The length of stay distribution for under 18s for all three census collections was similar.

⁶⁹ 17% and 60% were calculated from the raw data. Due to rounding, summing percentage figures for time bands can give a different figure.

Figure 31: Length of stay for patients under 18 years of age on census day 2013, 2014 and 2015



Base: All patients under 18 years old (160 in 2013 and 2014, 165 in 2015)

Suppression rules: * represents a figure less than 5 that has been suppressed. See 'Introduction' for

information on suppression rules. Due to suppression, figures may not sum.

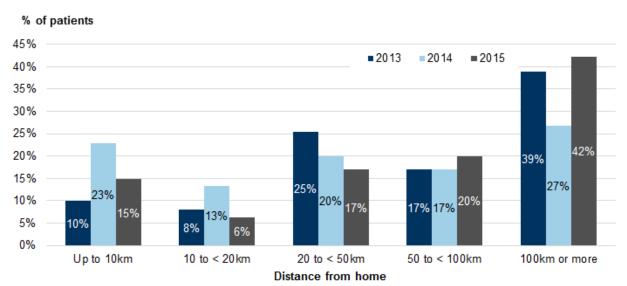
Note: Percentage of patients with length of stay over 5 years have been suppressed due to low numbers.

Distance from home for under 18s

On census day 2015, for 25 patients distance from home was unknown (this was 35 patients on census day 2014). Of the remaining patients the figures for the 2015 census compared to the 2014 census for the under 18 age group showed a sharp increase in the number of patients over 100km from home. HSCIC used the linked data to assess if these patients were in the previous census. Of the 60 people under 18 receiving care over 100km away, only 15 of the patients were receiving care in the 2014 census, this indicates that 45 are new episodes of care and the person is being placed far from home.

The distance from home distribution for the whole 2015 population had some differences to that for the under 18 population. The percentage of people 100km or more from home for those under 18 was 42% compared to 19% for the whole population. Similarly those with a distance from home of less than 10km was 15% for patients aged under 18 compared to 23% for the whole population.

Figure 32: Distance from home for patients under 18 years of age on census day 2013, 2014 and 2015



Data Source: Learning Disability Census 2015: Reference table 16

Base: All patients under 18 years old (160 in 2013 and 2014, 165 in 2015)

Suppression rules: * represents a figure less than 5 that has been suppressed. See 'Introduction' for

information on suppression rules. Due to suppression, figures may not sum.

Note: Percentage of patients with home address recorded as the same have been suppressed due to low

numbers

Linking 2013, 2014 and 2015 Learning Disability Censuses

Reference data tables: 29, 30a, 30b, 31

This section shows the results from linking all three census collections together on NHS number. There were 3,250 patients reported on in the 2013 census, 3,230 in the 2014 and 3,000 in the 2015. After linking on NHS number and logic criteria⁷⁰ there were 1,450 patients common to all three census collections, this represents just over 48% of the total patients reported on in 2015. The Background Methodology and Data Quality Report provides more detail on the linking process.

Figure 1 showed the total number of patients for each collection and how they all linked together. Linking at patient level on NHS number allows for three pieces of analysis:

- 1. Considering patients who were receiving inpatient care at the time of the 2014 census but not the 2015 census and so presuming that they are no longer in inpatient care: What are the characteristics of this group? What things appear to be associated with a greater chance of not being in inpatient care the following year? This relates to 3,230 patients in 2014 and 1,265 who did not appear in 2015 (530 + 735 from Figure 1)
- 2. Considering patients in all three census collections (1,450) and analysing what may have changed for them: How many patients have left hospital and been readmitted? How many have moved to a different ward/provider? If so, is it closer or further from home? Has the security level increased or decreased? Has their experience changed terms of medication and incidents?
- 3. Considering patients who receiving continuous care between 2014 and 2015 census collections, has their experience changed? More or fewer incidents? This relates to 1,620 patients (520+1,450 form figure 1 minus those who did not experience continuous care during this time as they left and were readmitted to hospital)

Patients receiving inpatient care at the time of 2014 census, but not receiving inpatient care at the time of the 2015 census

Considering patients reported on in the 2014 Learning Disability Census who were not receiving inpatient care on census day 2015 as a percentage of all patients within the 2014 census, an approximate to a 'rate of discharge' can be calculated for various measures. This provides an insight into the probability of receiving inpatient care on census day 2015 by various measures.

Note that as the census collections are a snap shot in time, a patient may have been in and out of care between the two census collections. This measure is just an approximated 'rate of discharge' and is shown by various measures.

Additional information on date of birth, gender and name were used to see if an NHS number match was a 'true' match. See the Methodology and Data Quality Report for more information.

Approximate rate of discharge

Of the 3,230 patients receiving inpatient care at the time of the 2014 census, 1,265 patients (39%) were no longer receiving inpatient care at the time of the 2015 census. The figure of 39% can be viewed as an approximate average rate of discharge. This exercise was undertaken for the 2014 census collection and the rate of discharge from the 2013 collection was also 39%. For more information see the comparable section in the 2014 census report⁷¹.

Reference data table 29 shows the results. Main points include:

Approximate rate of discharge by age and gender

Females had a greater rate of discharge than males at 50% in comparison to 35%. There also appears to be proportionally more occurrences of 'discharge' amongst children; 69% of patients aged under 18 in the 2014 census were not receiving inpatient care at the time of the 2015 Learning Disability Census. Over 65s had a slightly higher chance of discharge (47%) but some of this could be explained by age related deaths. These figures are all comparable with the rate of discharge from the 2013 census.

Approximate rate of discharge by Mental Health Act Status

Patients not subject to the Mental Health Act on census day had a noticeably higher rate of discharge at 73% (compared to 31% of those subject to the Mental Health Act on census day). This is to be expected since a patient detained under the Mental Health Act has been assessed as having a need for inpatient care until their current order ends. This is comparable to the 2013 census where 69% of patients not subject to the mental health act were discharged.

Approximate rate of discharge rate and ward security

The 'rate of discharge' increased as ward security level lowered. 55% of patients receiving care on a general ward were no longer receiving inpatient care on census day 2015 compared with 14% of patients resident on a high secure ward. This reflects the need for ongoing care due to the severity of the condition being treated as well as the use of the Mental Health Act. These figures are all comparable with the rate of discharge from the 2013 census.

Approximate rate of discharge rate by incidents

Incidents were considered by the groupings introduced in the 'Experience of care' section;

- adverse experiences (accidents, physical assault and self-harm);
- restrictive measures (hands on restraint and seclusion).

These were divided into groups according to whether a patient experienced no incidents; at least one adverse experience; at least one restrictive measure; or at least one adverse experience and one restrictive measure, all within the three months prior to census day. Considering discharge rate by these groupings suggests that those patients who had experienced at least one incident of an adverse experience and restrictive measure had a 'discharge rate' of 32%. Those who experienced no incidents had a 'discharge rate' of 45%. These figures are all comparable with the rate of discharge from the 2013 census.

⁷¹ http://www.hscic.gov.uk/catalogue/PUB16760

Approximate rate of discharge by care plan details

According to their care plan, 900 patients were reported to have a care plan record of 'working towards discharge to identified placement or with discharge plan in place'. This group had a 64% 'discharge rate'. This leaves 36% (325 patients) who at the time of the 2014 census were classed as working towards discharge but who were also receiving care at the time of the 2015 Learning Disability Census. This does not mean these 325 patients were not discharged and then readmitted between both census collections.

Patients who were 'Currently not dischargeable because of mental illness' were least likely to be discharged, showing a 'rate' of 22%. Furthermore, 59% patients who were recorded as 'delayed discharge' were no longer receiving inpatient care by the time of the 2015 census.

Approximate rate of discharge by length of stay and distance from home

There were some trends evident when looking at the length of stay of a patient and their distance from home. Table 18 shows the rate of discharge as per the distance from home as reported on in the 2014 Learning Disability Census collection.

Table 18: Approximate discharge rate by distance from home between census day 2014 & 2015

	2014	No longer in care at the time of the 2015 census	Approximate rate of discharge
All patients	3,230	1,265	39%
Distance from home			
Up to 10km	705	400	57%
10 to 20km	410	195	48%
20 to 50km	665	255	38%
50 to 100km	595	170	28%
100km or more	570	145	26%

Data Source: Learning Disability Census 2015. Reference data table 29

Base: All patients (3,230 in 2014. 2015 data was used to establish if a patient was also receiving inpatient care on census day 2015 and hence calculate the 'Approximate rate of discharge')

Suppression rules: * represents a figure less than 5 that has been suppressed. See 'Introduction' for information on suppression rules. Due to suppression, figures may not sum.

Patients up to 10km from home had a higher chance of 'discharge', where 57% were not receiving inpatient care at the time of the 2015 Learning Disability Census. However, patients more than 50km from home were half as likely to be discharged from inpatient facilities (around 27% of these patients had been 'discharged').

Table 19: Approximate discharge rate by length of stay between census day 2014 & 2015

	2014	No longer in care at the time of the 2015 census	Approximate rate of discharge
All patients	3,230	1,265	39%
Length of stay			
Up to three months	585	380	66%
Three months up to six months	320	170	53%
Six months up to one year	410	170	41%
One year up to two years	550	165	30%
Two years up to five years	800	230	29%
Five years up to ten years	390	105	27%
Ten years or more	175	45	26%

Base: All patients (3,230 in 2014. 2015 data was used to establish if a patient was also receiving inpatient care on census day 2015 and hence calculate the 'Approximate rate of discharge')

Suppression rules: * represents a figure less than 5 that has been suppressed. See 'Introduction' for information on suppression rules. Due to suppression, figures may not sum.

The trend is equally apparent for the length of stay. The longer a patient had been receiving inpatient care at the time of the 2014 Learning Disability Census the less chance they had of not receiving inpatient care at the time of the 2015 Learning Disability Census.

Patients receiving inpatient care at the time of all 3 census collections

This section considers the 1,450 patients who were receiving inpatient care at the time of all three census collections and considers differences and similarities between the results of the censuses.

Patients receiving care at the time of all three census collections and changes in hospital setting

There were 1,450 patients common to the 2013, 2014 and 2015 census collections. To try to establish what may have happened to these patients between the three census collections, each patient was assigned to one of three categories⁷²:

- Left hospital and readmitted;
- Moved ward (as part of continuous period of care);
- Same ward (as part of continuous period of care).

The aim of this was to determine whether a patient had moved between census day 2013, 2014 and 2015. Assigning records to categories was carried out by looking first at admission date in order to identify patients who left inpatient care and were later readmitted. Following

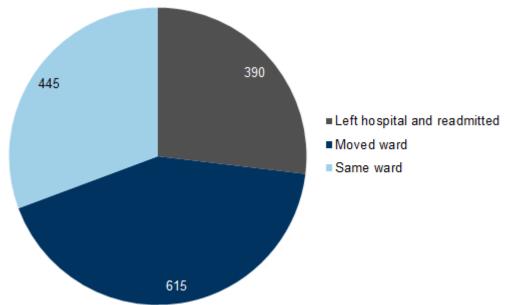
⁷² This analysis was also carried out for the 2014 census release and compared movement between 2013 and 2014. The categories also considered a move of provider. This was not included this year to reduce the risk of confusion due to providers buying one another out.

this, ward security level, ward service type, hospital postcode, and ward type were analysed. If a change had taken place in at least one of these factors between both census collections, the patient was classed as having 'moved ward', otherwise they were classed as having the 'same ward'. If the information was unknown in either year it is assumed to have stayed the same in each year.

Figure 33 shows that between the three census collections, (for the 1,450 patients who were receiving inpatient care at the time of all three census collections), 390 patients (27%) left inpatient care and were readmitted, 615 patients (42%) moved ward (as part of continuous period of care) and 445 patients (31%) remained in the same ward (as part of continuous period of care).

This analysis considers the change between all three census collections which are a snap shot in time. There will have been many patient admissions and discharges between the three collections and therefore, 390 is not a representation of total admissions and discharges within the three years, and some of these patients could have been in and out of inpatient care many times between the three census collections.

Figure 33: Patients who were receiving inpatient care at the time of both census collection; patient movement between 2013, 2014 and 2015 censuses



Data Source: Learning Disability Census 2015. Reference data table 30a Base: All patients receiving care at the time of the 2013, 2014 and 2015 census collections (1,450) Suppression rules: * represents a figure less than 5 that has been suppressed. See 'Introduction' for information on suppression rules. Due to suppression, figures may not sum.

Patients receiving care at the time of all three census collections and distance from home

It is possible to compare whether a patient has moved closer or further from home between 2013-2014 and 2014-2015. As shown earlier, distance from home can relate to length of stay as well as the rate of discharge. Distance from home is calculated using the postcode of the hospital and the home address and therefore in some cases, a change in distance from home could be due to a change of home address rather than a change in hospital ward. A patient could be in the same 'distance from home' band in all census collections and still be slightly closer or further away from home.

Table 20 shows the totals for changes in distance from home. Between the 2014 and 2015 Census collections patients were much more likely to stay the same distance from home (63%) compared to 2013 and 2014 (51%). Between 2013 and 2014 there appeared to be much more movement in general (both patients moving further and closer to home), in this time 41% (580 patients) moved compared to 27% (380 patients⁷³) between 2014 and 2015. Between 2014 and 2015 there was also a much lower percentage of people moving further from home (13% compared to 23%).

Table 20: For patients who were reported on in all 3 census collections, change in distance from home on census day between 2013-2014 and between 2014-2015

	Numb	er	Percent	
	2013-14	2014-15	2013-14	2014-15
All patients	1,450	1,450	100%	100%
Closer to home	255	200	18%	14%
Further from home	325	185	23%	13%
Same distance	735	910	51%	63%
Unknown	130	155	9%	11%

Data Source: Learning Disability Census 2015. Reference data table 30a Base: All patients receiving care at the time of both 2013, 2014 and 2015 census collections. Patients where distance from home was unknown were not included (1,320 in 2013/14 and 1,290 in 2014/15). Suppression rules: * represents a figure less than 5 that has been suppressed. See 'Introduction' for information on suppression rules. Due to suppression, figures may not sum.

Figure 34 shows how the ward distance from home varied through each of the 3 census collections for the patients who were reported on in each year. On the whole there were no major changes which reflects the data shown in Table 20.

⁷³ Figure shown here is based on unsuppressed figures and as such may not reflect the number shown in Table 20.

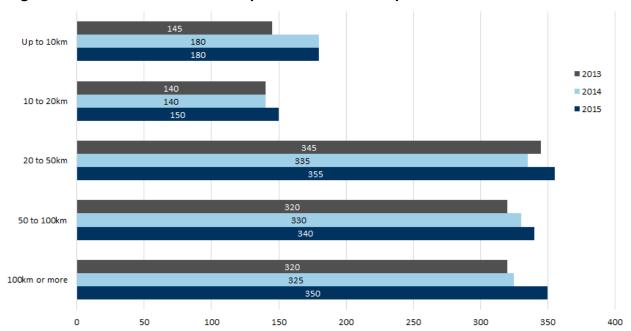


Figure 34: Distance from home for patients who were reported on in all 3 census collections.

Base: All patients receiving care at the time of the 2013, 2014 and 2015 census collections. Patients where distance from home was unknown or the same were not included (1,275 in 2013, 1,310 in 2014 and 1,380 in 2015).

Suppression rules: * represents a figure less than 5 that has been suppressed. See 'Introduction' for information on suppression rules. Due to suppression, figures may not sum.

Patients receiving care at the time of all three census collections and ward security level

Table 21 shows the total numbers of patients who had experienced a ward security level change between census collections. Between 2014 and 2015 the number of patients staying at the same security level increased from 75% (1,090 patients) between 2013 and 2014 to 80% (1,155 patients). Increases in security level went down from 8% (110 patients) between 2013 and 2014 to 4% (55 patients) between 2014 and 2015.

Table 21: For patients receiving care in both census collections, change in ward security level between census day 2013, 2014 and 2015

_	Numb	er	Perce	ent
	2013-14	2014-15	2013-14	2014-15
All patients	1,450	1,450	100%	100%
Reduced Security Level	245	240	17%	17%
Increased Security Level	110	55	8%	4%
Same Security Level	1,090	1,155	75%	80%

Data Source: Learning Disability Census 2015. Reference data table 30a Base: All patients receiving care at the time of both 2013, 2014 and 2015 census collections (1,450) Suppression rules: * represents a figure less than 5 that has been suppressed. See 'Introduction' for information on suppression rules. Due to suppression, figures may not sum.

Figure 35 shows which wards were being used by each of the 1,450 inpatients at the time of each census collection. This shows a year on year increase in the use of general wards. On census day 2013, 385 of the 1,450 patients were in a general security ward (27% of the

cohort). By 2015 this figure had increased to 625 patients (43% of the cohort). The number of patients in all of the secure settings fell between each of the 3 censuses.

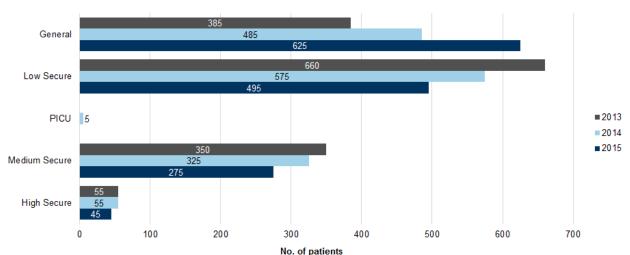


Figure 35: Ward security level for patients who were reported on in all 3 census collections.

Data Source: Learning Disability Census 2015. Reference data table 30b Base: All patients receiving care at the time of both 2013, 2014 and 2015 census collections (1,450) Suppression rules: * represents a figure less than 5 that has been suppressed. See 'Introduction' for information on suppression rules. Due to suppression, figures may not sum.

Patients receiving care in all three census collections and care plan details

This section considers whether a patient was ready for discharge at the time of all three census collections. A patient was classed as having a status of being 'ready for discharge' if the following responses to the question on details of their care plan were recorded:

- Working towards discharge to identified placement or with discharge plan in place;
- No onward placement available, delayed transfer of care.

A patient was classed as having a status of being 'not ready for discharge' if the following responses to the question on details of their care plan were recorded:

- Currently not dischargeable because of level of behaviour that presents a risk to the person or others, or mental illness;
- Currently receiving active treatment plan, discharge plan not in place;
- Requires indefinite IP care because of behavioural needs:
- Requires indefinite IP care because of physical needs.

This analysis considers differences between these two groupings for each patient in all three census collections. Figure 36 shows that 745 patients (52%) were receiving care during each census collection but were not classed as being ready for discharge by their care plan during any of the census collections. 50 patients were described as ready for discharge in all 3 years, additional analysis to investigate if these people were part of the group who left hospital and were readmitted was not undertaken.

There is no distinction made about which of the years the patient was ready to discharge.

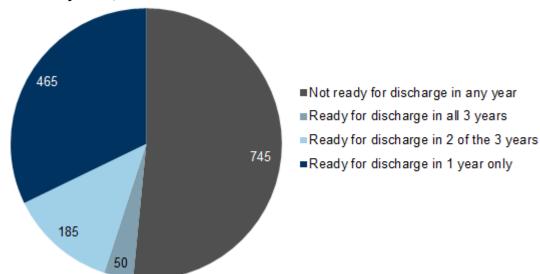


Figure 36: For patients receiving care in all three census collections, change in care plan between census day 2013, 2014 and 2015

Data Source: Learning Disability Census 2014. Reference data table 30a Base: All patients receiving care at the time of the 2013, 2014 and 2015 census collections (1,450) Suppression rules: * represents a figure less than 5 that has been suppressed. See 'Introduction' for information on suppression rules. Due to suppression, figures may not sum.

Patients receiving continuous inpatient care between the 2014 and 2015 census collections

Reference data table 31 considers those patients who did not leave hospital at all between the 2014 and 2015 census collections. Patients were first identified by linkage on NHS number and logic, and then total length of stay as calculated in 2015 was used to remove any patient who had not received continuous inpatient care between both collections. This gives a total of 1,620 patients (54% of the 2015 headcount) who were receiving continuous inpatient care between 2014 and 2015 census collections. The following analysis picks out key measures to investigate whether there has been any change in these areas for these patients. All three census collections were not used for this analysis since considering changes in care for three points in time adds additional complexity to the data.

Patients receiving continuous inpatient care between 2014 and 2015 census collections and incidents

Figure 37 shows the changes in the number of incidents per year for the 1,620 patients who were receiving continuous care between both census collections. The 2013 collection collected responses in bands such as 1-5, 6-10. For all types of incidents, the majority of patients did not experience any incidents in either year. Seclusion was the least experienced incident type with 81% (1,315 patients) not experiencing it in either year. For all incident types, more patients experienced a decrease in the number of incidents experienced rather than an increase.

Adverse experiences Self harm 66% 14% 11% 10% Accidents 67% 14% Restrictive measures Physical assault 65% 15% 13% 53% Hands on restraint 19% 13% 15% 81% Seclusion 0% 10% 20% 30% 40% 50% 60% 70% 80% 90% 100% % of patients ■ No incidents either year Less incidents in 2015 ■ More incidents in 2015 Same band of incidents

Figure 37: For patients receiving care in 2014 and 2015 census collections, change in experience of incidents (three months prior to census day) between census day 2014 & 2015

Data Source: Learning Disability Census 2014 & 2015. Reference data table 31 Base: All patients receiving continuous inpatient care between both 2014 & 2015 census collections (1,620) Suppression rules: * represents a figure less than 5 that has been suppressed. See 'Introduction' for information on suppression rules. Due to suppression, figures may not sum.

Patients receiving continuous inpatient care between 2014 and 2015 census collections and medication

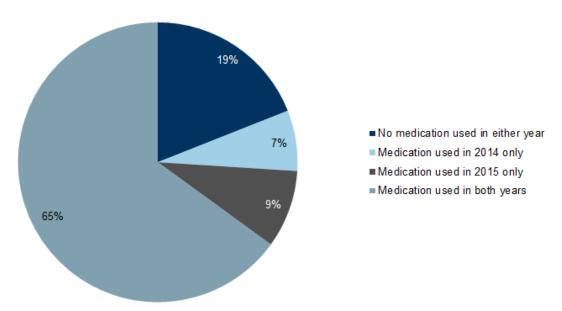
Figure 38 considers the change in the use of antipsychotic medication for patients receiving continuous inpatient care between 2014 and 2015. Antipsychotic medication was classed as being used regularly, PRN⁷⁴ or both. For both collections, the question considered the use of the antipsychotic medication in the 28 days prior to census day.

For 65% (1,050 patients), antipsychotic medication was used in both years. Only 19% (310 patients) did not receive any medication during the 28 days prior to either census collection. 7% (115 patients) received this medication only during the three months prior to the 2014 collection and for 9% (145 patients) medication usage was reported for the 28 days prior to the 2015 census collection but not the 2014 collection.

Copyright © 2015, Health and Social Care Information Centre. All rights reserved.

^{74 (}Pro Re Nata; 'as needed')

Figure 38: For patients receiving care in both census collections, change in use of antipsychotic medication used (28 days prior to census day) between census day 2014 & 2015



Data Source: Learning Disability Census 2015. Reference data table 31
Base: All patients receiving continuous inpatient care between both 2014 & 2015 census collections (1,620)
Suppression rules: * represents a figure less than 5 that has been suppressed. See 'Introduction' for information on suppression rules. Due to suppression, figures may not sum.

Patients receiving continuous inpatient care between the 2014 and 2015 census collections and agreements

Reference data table 31 considers agreements with both the commissioner and the community clinical team regarding patient care. Of the 1,620 patients who did not leave continuous care during both census collections, there were only 20 patients (1%) who did not have their care plan agreed with the commissioner in either 2014 or 2015. Similarly there were only 95 patients (6%) whose care plan was not agreed with the community clinical team in either year. 1,520 patients (94%) had their care plan agreed with the community clinical team in both years.

Considering patients who had agreements in 2014 but not in 2015, this was the case for 110 patients (7%) for community clinical team and 55 patients (3%) for commissioner. This could be explained by patients who have moved ward or provider close to census date and agreements have not yet been set up. This has not been investigated in this report.

Agreed with community clinical team?

Agreed with commissioner?

94%

3% 1%

1%

0% 20% 40% 60% 80% 100%

% of patients

Agreed both years Not agreed in 2014, agreed in 2015 Not agreed in 2015, agreed in 2014 Not agreed in either year

Figure 39: For patients receiving care in both census collections, change discussions (with commissioners and clinical teams) between census day 2014 & 2015

Data Source: Learning Disability Census 2015. Reference data table 31 Base: All patients receiving continuous inpatient care between both 2014 & 2015 census collections (1,620) Suppression rules: * represents a figure less than 5 that has been suppressed. See 'Introduction' for information on suppression rules. Due to suppression, figures may not sum.

Reference data table 31 also shows changes in types of discussions; with commissioners, care managers and clinical teams. The majority of those receiving continuous care between both years 1,455 patients (90%) had some sort of discussion in both years. However for 25 patients (2%) they did not have any discussions of any kind in either year.

Linking the Learning Disability Census to Assuring Transformation

Reference data tables: 33, 34, 35, 36, 37

Originally conceived and collected by NHS England, the purpose of the 'Assuring Transformation' data collection was to ensure that the public were 'aware of NHS commitments within the Transforming Care Programme'. Data were collected from commissioners of learning disability services on a quarterly basis, and published on the NHS England website⁷⁵. From January 2015, responsibility for its collection and publication were transferred to the HSCIC⁷⁶. This addressed key requirements around the improvement of data quality and reporting frequency. The revised collection methodology supports real time data capture; it is a "live" system that commissioners are required to update as and when changes occur in the care of a patient who falls within scope of the collection.

The HSCIC currently take a snapshot of the data at the end of each month and report on these data on a monthly, quarterly and annual basis. HSCIC has undertaken work to link the patients in the Assuring Transformation collection with the Learning Disability Census 2015. Linking was carried out using the same method used to link the 2013, 2014 and 2015 census collections whereby the initial link is done on NHS number then additional logic is applied to ensure the link is 'true'.

⁷⁵ http://www.e<u>ngland.nhs.uk/ourwork/qual-clin-lead/ld/atd/</u>

⁷⁶ Assuring Transformation is a commissioner based return. Further information can be found at www.hscic.gov.uk/assuringtransformation.

The position at the end of September 2015 as of the October report from the Assuring Transformation⁷⁷ was used, this allowed for the most up to date position for Assuring Transformation data to be used. More information on the linking process can be found in the Background data quality and methodology report.

After linking the data, it was found that 2,140 patients were common between both the Learning Disability Census and Assuring Transformation collections. Of the 3,000 patients in the 2015 Learning Disability Census, this leaves 855 patients who do not appear in the Assuring Transformation collection.

Similarly of the 2,625 patients in the Assuring Transformation collection at the end of September, 480 do not appear in the Learning Disability Census. These numbers suggest that there are around 3,480 patients who meet the scope criteria for both of these collections. Figure 40 explains the relationship.

Assuring Transformation:

• 2,625 total patients

• 480 patients do not appear in the Learning Disabilities Census 2015.

Common Patients:

• 2,140 patients appear in both the Assuring Transformation collection and the Learning Disabilities Census 2015.

Figure 40: Diagram to show how the Assuring Transformation collection links with the Learning Disability Census 2015.

Data Source: Learning Disability Census 2015. Reference data table 33, 35

Base: All patients (3,000 in LDC 2015, 2,625 in AT for September 2015 as calculated at the end of October 2015)

Suppression rules: * represents a figure less than 5 that has been suppressed. See 'Introduction' for information on suppression rules. Due to suppression, figures may not sum.

Scope differences

The Assuring Transformation collection is a commissioner based collection. Data are provided by English commissioners and healthcare is typically provided in England (although care commissioned in England and provided elsewhere in the UK will be included). There is a slight difference in scope between this collection and the Learning Disability Census since the Census comprises data from providers based only in England, but does include care provided in England but commissioned from other UK countries. Figure 41 shows the difference in scope for the two collections. This difference in scope means that some

76

⁷⁷ For the report see: http://www.hscic.gov.uk/pubs/ldsmoct15

patients would not be expected to link to the other collection. .The methodology and background data quality include additional information on how this was calculated. For the following comparison exploration and investigating into where the unreported people are, all those identified as unreported have remained in the analysis.

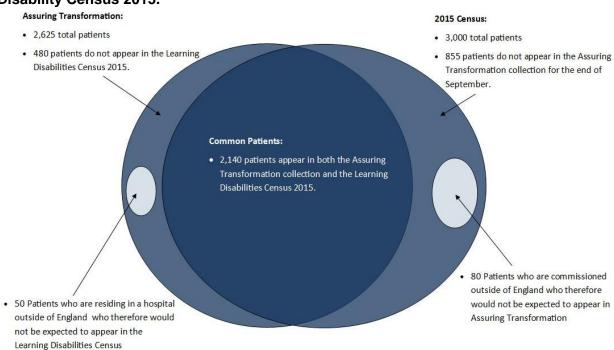


Figure 41: The link between the Assuring Transformation collection and the Learning Disability Census 2015.

Data Source: Learning Disability Census 2015.

Base: All patients (3,000 in LDC 2015, 2,625 in AT for September 2015 as calculated at the end of October 2015)

Suppression rules: * represents a figure less than 5 that has been suppressed. See 'Introduction' for information on suppression rules. Due to suppression, figures may not sum.

Differences by commissioner

To try and understand the differences, HSCIC looked at those who did and did not link by commissioner. For Assuring Transformation this was the CCG who is responsible for submitting the data. For the Learning Disability Census there are three commissioner measures that could have been used; derived CCG of ward/hospital as calculated from the postcode; CCG Organisation code; and which commissioner was identified by Q48a – Q48g on who was paying for the care. Organisation code of commissioner and who was paying for care have been investigated further⁷⁸.

As Assuring Transformation does not ask who is paying for care the split cannot go any lower than CCG/Hub. The high level figures are shown in Table 22. Of those unreported in Assuring Transformation, the data implies 455 (53%) were paid for by CCGs, and 275 (32%) were paid for by Hubs. Of those unreported in the Census, 285 (59%) were commissioned by CCGs and 195 (41%) were commissioned by Hubs. Reference data tables 33-36 show more detail at commissioner level.

⁷⁸ See the background methodology and data quality as the responses to this question were grouped

Table 22: Linking the Learning Disability Census to Assuring Transformation, results by Submitting CCG for Assuring Transformation and Paying CCG for the Learning Disability Census

	Learning Disability Census 2015	Linked to Assuring Transformation	Not linked to Assuring Transformation	Assuring Transformation	Linked to Learning Disability Census 2015	Not linked to Learning Disability Census 2015
All patients	3,000	2,140	855	2,625	2,140	480
Organisation						
CCG total	1,335	880	455	1,230	950	285
Specialised commissioning (NHS England) total	1,470	1,195	275	1,390	1,195	195
Other NHS commissioner outside England	75	*	70	-	-	
Other NHS provider	25	5	15	-	-	
Pooled budget	10	10	*	-	-	
Local authority	80	45	35	-	-	
Private funding	*	*	*	-	-	
Non UK commissioning	*	*	*	_	_	

Data Source: Learning Disability Census 2015. Reference data table 33, Assuring Transformation October release

Base: All patients (3,000 in 2015 Learning Disability Census, 2,625 in Assuring Transformation) Suppression rules: * represents a figure less than 5 that has been suppressed. See 'Introduction' for information on suppression rules. Due to suppression, figures may not sum.

Reference data table 33 (part b) considers those reported in the Learning Disability Census and not in Assuring Transformation by the recorded commissioner in the 2015 Census. Of the 855 not linked to Assuring transformation 470 were commissioned by CCGs, 170 by NHS England Specialist Commissioning Hubs and 75 were commissioned outside the England.

All patients unreported in either collection

In total there are 1,340⁷⁹ patients unreported in either the Learning Disability Census 2015 or the Assuring Transformation collection at the end of September. Of the 480 patients unreported in the Learning Disability Census 2015, 100 of these were also unreported in the Learning Disability Census 2014. Of the 855 patients unreported in the Assuring Transformation at the end of September 2015, 240 were also unreported in the Assuring Transformation collection at the end of September 2014.

The following graphs and charts look in more detail at the 1,340 patients unreported in either collection. In each case the percentages in the graph are a percentage of the total unreported patients (1,340). The total of each measure will add up to 100% in each instance. Where figures are referenced, the total has been calculated from the raw data and then suppressed so may not match the reference tables. For example reference data tables may show 10 people unreported in Assuring Transformation and 5 from the Learning Disability Census for a key measure. However the total may be 20 not 15 due to rounding.

Reference data table 37 shows additional measures.

⁷⁹ Due to rounding, the number unreported (1,340) is different by 5 from 480+855 as shown in Figure 40

Patients unreported in either collection by region

Postcode of hospital was collected from both data collections; this can be used to calculate a derived region of hospital. The Learning Disability Census asks for postcode of home address. This is sent to the tracing service to enable unknown postcodes to be completed where possible. The Assuring Transformation collection did not ask for postcode of home address, however, the tracing service allowed for retrieval of this by NHS number. For both the census and assuring transformation, the postcode of home address was used to create the derived region of residence.

Figure 42 shows the patients unreported in either collection by region of hospital. 16% of the patients unreported in either collection (215 patients) are located in the East Midlands; this is the highest for any region. The number of people unreported in the South East (8%, 105 patients) and South West (2%, 30 patients) is lower compared to the other regions. Figure 43 shows the patients unreported in either collection by region of residence. There is a more even spread of patients compared to the region of hospital calculation. London is the biggest region of residence for the unreported patients with 170 patients unreported (13%).

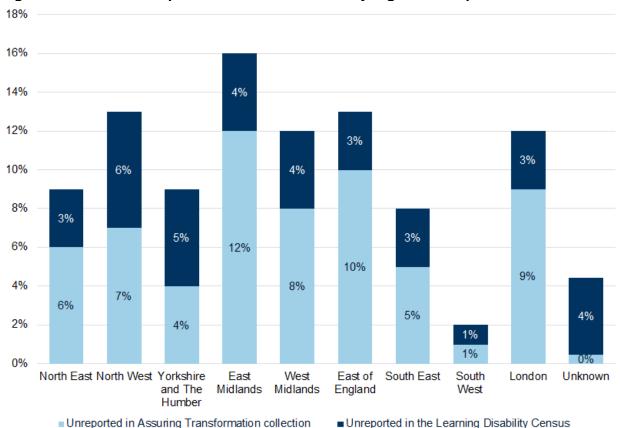


Figure 42: Patients unreported in either collection by region of hospital

Data Source: Learning Disability Census 2015. Reference data table 37

Base: All patients who are unreported in either the Learning Disability Census or Assuring Transformation collections (1,340)

Suppression rules: * represents a figure less than 5 that has been suppressed. See 'Introduction' for information on suppression rules. Due to suppression, figures may not sum.

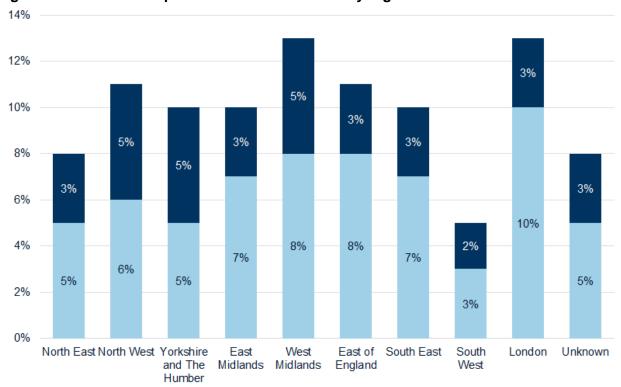


Figure 43: Patients unreported in either collection by region of residence

Unreported in Assuring Transformation collection

■ Unreported in the Learning Disability Census

Data Source: Learning Disability Census 2015. Reference data table 37

Base: All patients who are unreported in either the Learning Disability Census or Assuring Transformation collections (1,340)

Suppression rules: * represents a figure less than 5 that has been suppressed. See 'Introduction' for information on suppression rules. Due to suppression, figures may not sum.

Patients unreported in either collection by ward characteristics

Figure 44 shows that of those unreported in either collection the majority of patients were in General ward settings. 860 (64%) of the 1,340 patients were located in General wards. The breakdown of those unreported by ward type is shown in Figure 45. The other 36% were in secure settings. This is backed up by Figure 44 where 32% (430 patients) were described as being in a 'low, medium or high secure forensic bed'

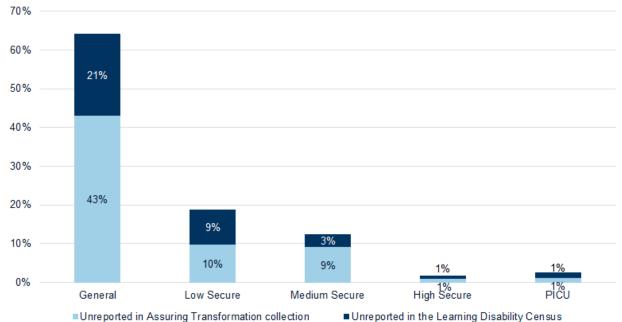


Figure 44: Patients unreported in either collection by ward security level

Data Source: Learning Disability Census 2015. Reference data table 37

Base: All patients who are unreported in either the Learning Disability Census or Assuring Transformation collections (1,340)

Suppression rules: * represents a figure less than 5 that has been suppressed. See 'Introduction' for information on suppression rules. Due to suppression, figures may not sum.

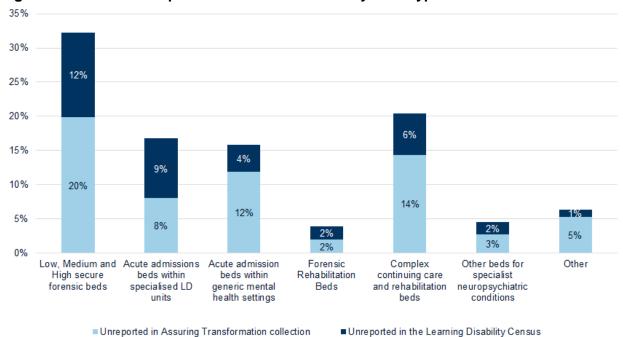


Figure 45: Patients unreported in either collection by ward type

Data Source: Learning Disability Census 2015. Reference data table 37

Base: All patients who are unreported in either the Learning Disability Census or Assuring Transformation collections (1,340)

Suppression rules: * represents a figure less than 5 that has been suppressed. See 'Introduction' for information on suppression rules. Due to suppression, figures may not sum.

Patients unreported in either collection by care plan

Figure 46 shows that of the unreported patients, 38% (510 patients) were receiving an active treatment plan with no discharge plan in place. An additional 27% (365 patients) were classed as not dischargeable or requiring indefinite inpatient care. 65 patients (5%) were classed as being ready for discharge but with no onward placement available.

Additionally of those unreported in Assuring Transformation, 84% (725 patients) had had their care plan agreed by the commissioner either in the past year or during the placement as a whole. Of those unreported in the Learning Disability Census 2015, 265 (55%) had had their plan for discharge agreed by the provider clinical team.

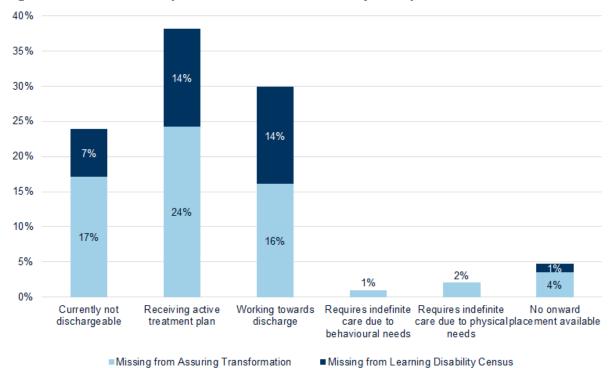


Figure 46: Patients unreported in either collection by care plan details

Data Source: Learning Disability Census 2015. Reference data table 37

Base: All patients who are unreported in either the Learning Disability Census or Assuring Transformation collections (1,340)

Suppression rules: * represents a figure less than 5 that has been suppressed. See 'Introduction' for information on suppression rules. Due to suppression, figures may not sum.

Patients unreported in either collection by Mental Health Act status on admission

Figure 47 shows that of those unreported in either collection 74% (985 patients) were detained under the Mental Health Act on admission to hospital. Of the patients detained, the majority were detained under the Mental Health Act Part 2 (640 patients, 48%). 26% of the unreported patients were not detained under the Mental Health Act (350 patients).

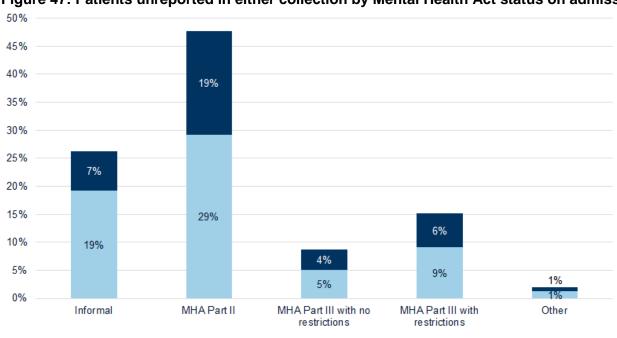


Figure 47: Patients unreported in either collection by Mental Health Act status on admission

■ Unreported in Assuring Transformation collection ■ Unreported in the Learning Disability Census

Data Source: Learning Disability Census 2015. Reference data table 37
Base: All patients who are unreported in either the Learning Disability Census or Assuring Transformation collections (1,340)

Suppression rules: * represents a figure less than 5 that has been suppressed. See 'Introduction' for information on suppression rules. Due to suppression, figures may not sum.

Comparison of estimated totals for the 2013, 2014 and 2015

Based on the work to link the 3 census collections and the work to link Assuring Transformation with the Learning Disability Census 2015, HSCIC have been able to produce figures for the estimated total population who would have been in scope for the census in each year. Based on the dates of first admission provided as part of the Learning Disability Census 2015 it was estimated that an additional 295 patients should have appeared in the 2013 census. Also based on the first admission dates from 2015, 245 patients should have appeared in the 2014 Census. This would give a total of 3,545 for 2013 and 3,475 for 2014.

The work on linking Assuring Transformation with the 2015 Learning Disability Census revealed 480 patients in Assuring Transformation at the end of September who did not appear in the census. If these patients had been included the total figure would have been around 3,480. These figures are shown below in figure 48.

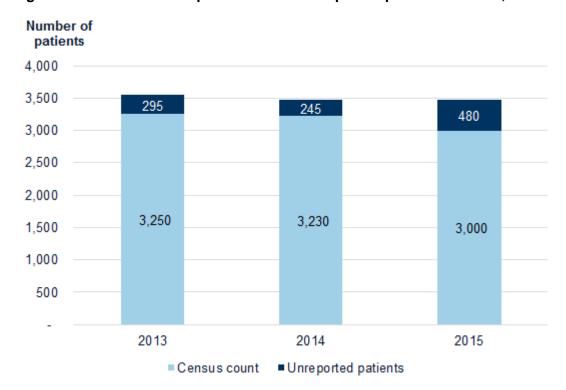


Figure 48: Census counts plus estimated unreported patients for 2013, 2014 and 2015

Data Source: Learning Disability Census 2015. Data are not reflected in a reference table. Base: All patients (3,250 in 2013, 3,230 in 2014, and 3,000 in 2015) 2,625 in Assuring Transformation Suppression rules: * represents a figure less than 5 that has been suppressed. See 'Introduction' for information on suppression rules. Due to suppression, figures may not sum.

These figures show that there is still work to be done in terms of obtaining full coverage of inpatients with learning disabilities and/or autism. The Learning Disability Census is not likely to take place again, but it is expected that comparable data will come from the Mental Health Services Data Set (MHSDS). However the Assuring Transformation collection will continue to be collected by HSCIC in its current form for some time.

To try and encourage full compliance to the Assuring Transformation collection and the MHSDS, HSCIC plan to write to commissioners and providers in regards to the patients

unreported in each collection with the expectation that MHSDS and Assuring Transformation gain better coverage.

For the 855 patients unreported in the Assuring Transformation collection, the data will be shared with NHS England for them to contact the commissioners to establish whether the patient needs to be added to the Assuring Transformation collection. This will enable the Assuring Transformation to continue to improve data coverage.

For the 480 unreported in the 2015 Learning Disability Census, the providers will be contacted and told that commissioners are reporting patients in their care. The providers will be asked to verify this and to ensure going forward that MHSDS is updated accurately.

End note

Comparing total counts and including people who appear to be unreported in the 2013 and 2014 Learning Disability Census as indicated by the 2015 census and those unreported in the 2015 Learning Disability Census as indicated by the Assuring Transformation collection, indicates that there is not much change between the inpatient learning disability populations between all three census collections. It is worth remembering that the Learning Disability Census collections are just a snapshot in time and fluctuations between the collections cannot be seen here.

This report does however continue to provide a definitive baseline from which to implement the actions raised in several reports, most recently 'building the right support'⁸⁰ which aims to reduce the number of inpatients over the next 5 years.

⁸⁰ https://www.england.nhs.uk/wp-content/uploads/2015/10/ld-nat-imp-plan-oct15.pdf

Annex 1: Mental Health Act groupings used

The Mental Health Act groupings used for the section on 'reasons for admission and remaining in care' are shown below:

Groups	Legal status			
Informal	Informal			
Mental Health Act Part II	Section 2			
	Section 3			
Mental Health Act Part III, no restrictions	Section 35			
	Section 36			
	Section 37			
	Section 38			
	Section 44			
	Section 45A			
	Section 45A (Limitation Direction Ended)			
	Section 45A (Limited Direction in Force)			
	Section 47			
	Section 48			
Mental Health Act Part III, with restrictions	Section 37 with section 41 restrictions			
	Section 47 with section 49			
	Section 48 with section 49 restrictions			
Other	Formally detained under Criminal Procedure(Insanity) Act 1964 as amended by the Criminal Procedures (Insanity and Unfitness to Plead) Act 1991 Formally detained under Mental Health Act Section 135			
	Formally detained under Mental Health Act Section 136			
	Formally detained under Mental Health Act Section 4 Formally detained under Mental Health Act Section 5(2)			
	Formally detained under Mental Health Act Section 5(2) Formally detained under Mental Health Act Section 5(4)			
	Formally detained under Merital Health Act Section 5(4) Formally detained under other acts			
	Subject to guardianship under Mental Health Act Section 7			
	Subject to guardianship under Mental Health Act Section 7 Subject to guardianship under Mental Health Act Section 37			
	Oubject to guardianship under Mental Fleath Act Occilon 37			

Annex 2: Related reading

Historical versions of this publication:

Learning Disability Census 2013 – Initial findings http://www.hscic.gov.uk/catalogue/PUB13149

Learning Disability Census 2013 – Further analysis http://www.hscic.gov.uk/catalogue/PUB14046

Learning Disability Census 2014 – Initial findings

http://www.hscic.gov.uk/catalogue/PUB16760

Learning Disability Census 2014 – Further analysis

http://www.hscic.gov.uk/catalogue/PUB17469

Other documentation listed below concerning this publication can be found at: http://www.hscic.gov.uk/ldcensus

- Letter introducing the Learning Disability Census and invitation to attend awareness events.
- Guidance notes
- Frequently asked questions
- Operational guidance
- Easy read leaflet
- Awareness event presentation slides
- User registration form

Background documentation and resources concerning this publication:

Winterbourne View Hospital: Department of Health review and publications https://www.gov.uk/government/publications/winterbourne-view-hospital-department-of-health-review-and-response

Winterbourne View Joint Improvement Programme http://www.local.gov.uk/place-i-call-home

South Gloucestershire Safeguarding Adults Board Winterbourne View Hospital A Serious Case Review

http://hosted.southglos.gov.uk/wv/report.pdf

Suggested reading:

Winterbourne view – time for change: Transforming the commissioning of services for people with learning disabilities and/or autism

http://www.england.nhs.uk/wp-content/uploads/2014/11/transforming-commissioning-services.pdf

People with learning disability and mental health, behavioural or forensic problems: the role of inpatient services: Faculty Report FR/ID/03 July 2013

http://www.rcpsych.ac.uk/pdf/FR%20ID%2003%20for%20website.pdf

This report gives background to the development of current in patient provision,/ argues for a range of provision to meet complex needs and presents a reclassification of inpatient assessment and treatment options available.

Eric Emerson et al. "People with Learning Disabilities in England, 2012", (Improving Health and Lives: Learning Disability Observatory, 2013),

http://www.improvinghealthandlives.org.uk/gsf.php5?f=17280&fv=18581

The publication aims to provide a summary of information on the characteristics of people with learning disabilities, the services and supports they use as collected by numerous government departments.

Pauline Heslop et al, "Confidential Inquiry into premature deaths of people with learning disabilities (CIPOLD): Final report", (University of Bristol, 2013) http://www.bris.ac.uk/cipold/fullfinalreport.pdf

The Confidential Inquiry into the deaths of people with learning disabilities (CIPOLD) was tasked with investigating avoidable or premature deaths of people with learning disabilities through a series of retrospective reviews of deaths. (Considering 247 deaths between 2010 and 2013). The aim was to review the patterns of care that people received in the period leading up to their deaths. It identified deficient health and social care provision.

Services for People with learning Disabilities and Challenging Behaviour or Mental Health Needs: Report Of A Project Group Chairman: Prof J L Mansell) Revised Edition October 2007 http://www.kent.ac.uk/tizard/research/research_projects/dh2007mansellreport.pdf

The report recognised people with learning disabilities whose behaviour challenges are among those most at risk of services breaking down and the need to change the nature of commissioning to build and sustain the capacity to meet the needs of people in each area

Joint investigation into the provision of services for people with learning disabilities at Cornwall Partnership NHS Trust. (Commission For Health Care Audit And Inspection 2006) http://webarchive.nationalarchives.gov.uk/20060502043818/http://healthcarecommission.org.uk/_db/documents/cornwall_investigation_report.pdf (note: this link will only work if copied and pasted into a browser)

This report considered practice standards within the Trust. The investigation uncovered abuse, provision that was inconsistent with the principles of Valuing People (in that individuals' rights, choice, inclusion and independence were not reflected in practice), provision within in unacceptable environments, and failings in planning and review of care.

Investigation into the service for people with learning disabilities provided by Sutton and Merton Primary Care Trust (Healthcare Commission, 2007)

http://webarchive.nationalarchives.gov.uk/20060502043818/http://healthcarecommission.org.uk/_db/_documents/Sutton_and_Merton_inv_Main_Tag.pdf_(note: this link will only work if copied and pasted into a browser)

This report detailed deficiencies in the provision of services to people with learning disabilities. Issue were revealed concerning the quality of health care received and level of activity provision. Of particular relevance was the inappropriate use of restraint, lack of policy and adequacy of staff training.

Valuing People: A New Strategy for Learning Disability for the 21st Century. https://www.gov.uk/government/uploads/system/uploads/attachment_data/file/250877/5086.pdf
This white paper introduced the principles of rights, independence, choice and inclusion. It was at the time of publication the first white paper on learning disabilities for 30 years and enjoyed cross Governmental backing. It considered a lifelong approach with proposals set to effect improved outcomes relating to health and social services, education, housing and employment for people with learning disabilities and to include families and carers in decision making.

Challenging behaviour and learning disabilities: prevention and interventions for people with learning disabilities whose behaviour challenges (NICE guideline Published: 29 May 2015 nice.org.uk/guidance/ng11).

http://www.nice.org.uk/guidance/ng11/resources/challenging-behaviour-and-learning-disabilities-prevention-and-interventions-for-people-with-learning-disabilities-whose-behaviour-challenges-1837266392005

These guidelines inform best practice when providing services to people who's behaviour may challenge the provision of services. The guidance informs Nice Quality standard QS101 Challenging behaviour and learning disabilities. https://www.nice.org.uk/guidance/gs101

Positive and Proactive Care: reducing the need for restrictive measures

https://www.gov.uk/government/uploads/system/uploads/attachment_data/file/300293/JRA_DoH_Guidance_on_RP_web_accessible.pdf

This guidance seeks to provide a framework to support the development of service cultures and ways of delivering care and support to better meet needs and improve quality of life. It provides key actions to reduce the need for restrictive measures and promote recovery.

British Institute of Learning Disability, Factsheet: Chemical restraint http://www.bild.org.uk/EasysiteWeb/getresource.axd?AssetID=2516&type=full&servicetype=Attachm ent

This fact sheet provides a brief summary of what chemical restrain is, its uses, and context of use.

Mind, Mental Health Crisis Care: Physical Restraint In Crisis A Report On Physical Restraint In Hospital Settings In England. (June 2013)

This report discussed the use of physical restraint and its consequences on people being restrained. The report sought ending face down restraint and the development of national standards and development of accredited training for staff.

Building the right support

Describes the national plan to develop community services and close inpatient facilities for people with a learning disability and/or autism who display behaviour that challenges, including those with a mental health condition.

https://www.england.nhs.uk/wp-content/uploads/2015/10/ld-nat-imp-plan-oct15.pdf

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

Responsible Statistician

Chris Buttery, Section Head ISBN 978-1-78386-574-1

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

For further information

www.hscic.gov.uk 0300 303 5678 enquiries@hscic.gov.uk

Copyright © 2015 Health and Social Care Information Centre. All rights reserved.

This work remains the sole and exclusive property of the Health and Social Care Information Centre and may only be reproduced where there is explicit reference to the ownership of the Health and Social Care Information Centre.

This work may be re-used by NHS and government organisations without permission.