

Benefits case study

‘Learning Disabilities Census’ (2013) publication

**Improving services and outcomes for patients with
learning disabilities, autistic spectrum disorders and
behaviour that challenges**

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1 Version History

Version	Date	Summary of key changes
1.0	27/03/2015	First release.
1.1	30/07/2015	<ul style="list-style-type: none">• Included information on how the Challenging Behaviour Foundation (CBF) and Mencap have used the Learning Disabilities Census 2013 (Census 2013) publications.• Minor grammatical changes to improve readability

2 Purpose of case study

In 2013, the Health and Social Care Information Centre (HSCIC) collected data for the Learning Disabilities Census ('Census 2013'), as a result of a requirement laid out in the *Transforming care: A national response to Winterbourne View Hospital* report. The census findings were released in two HSCIC publication outputs - 'Learning Disabilities Census Report' (2013)¹ and 'Learning Disabilities Census Report – Further analysis' (2013)².

The purpose of this case study is to describe:

- how stakeholders, such as the Department of Health (DH), NHS England, Public Health England (PHE), Joint Improvement Programme (JIP), charities and Care Quality Commission (CQC) have used these two publications and, in some cases, the Census's underlying data; and
- whether those uses have delivered improved outcomes and/or realised measurable benefits (measurable improvements) for commissioners, providers, learning disabled patients and other stakeholders. Further detail on the outcomes and benefits is available in [section 8](#).

The Census 2013 publications and the underlying data provide information that enables commissioners, providers and other stakeholders to make informed changes to the delivery of services. These changes may lead to improved outcomes and measurable benefits. This case study aims to show the connection between the Census 2013 publications and the outcomes and benefits (where realised).

The HSCIC has also undertaken the same census in 2014 ('Census 2014') and the resulting report (first in a series of two) was published in January 2015³. A follow-up 'further analysis' report was published in April 2015⁴.

3 Learning Disabilities Census 2013

3.1 Inclusion criteria

The Census 2013 collected patient-identifiable data for individuals who:

- had a learning disability, autistic spectrum disorder (including Asperger's syndrome) and/or behaviour that challenges; and

- were inpatients in specialist facilities providing mental and behavioural healthcare or psychiatric in-patient care, but not providing physical health interventions at midnight on 30 September 2013.⁵ Examples of specialist facilities include specialist assessment and treatment units (ATUs), general psychiatric units and secure units.⁶

Based on the 104 provider organisations (58 NHS providers and 46 independent providers) that returned data, there were 3,250 service users⁷ who met the Census 2013 inclusion criteria.

3.2 Example findings

The Census 2013 collected a range of information about learning disabled people (who were in inpatient facilities) and their treatment environment, including demographics, ward characteristics and information relating to out of area placements and length of stay. Examples of findings highlighted in Census 2013 publication outputs include:

- 1,949 (60%) people had been inpatients for a year or more, and 572 (18%) had been inpatients for five years or more.⁸
- Just under one in five inpatients (18.2% or 570) were staying in wards located 100km or more from their residential postcode.^{1 9}
- Around one in seven service users (16%, or 512 people) were in medium secure wards; few (2% or 73 people) were inpatients in high secure wards.¹⁰

Further information on the Census 2013 findings is available from <http://www.hscic.gov.uk/catalogue/PUB13149> and <http://www.hscic.gov.uk/catalogue/PUB14046>. A selection of measures relating to Census 2013 (and Census 2014) is also available from [section 7](#).

4 Learning Disabilities Census 2013 driver

In May 2011, the BBC One Panorama programme 'Undercover Care: The Abuse Exposed', reported on the mistreatment and assault of adults with learning disabilities and autistic spectrum disorder within Winterbourne View Hospital.¹¹ In response, 3 key reports were published:

1. *South Gloucestershire Safeguarding Adult Board published A Serious Case Review*¹²
2. *Department of Health Review: Winterbourne View Hospital, Interim Report*¹³
3. *Transforming care: A national response to Winterbourne View Hospital*¹⁴ and the accompanying *Concordat: Programme of Action*¹⁵.

Transforming care: A national response to Winterbourne View Hospital (report three above) contained a detailed timetable of 63 national actions², including:

¹ The denominator is based on the number of patients with a valid postcode (which includes patients for whom the hospital postcode was provided as their residential postcode). The same indicator is also specified in section 7, but there it uses a different denominator, hence the section 7 outturn is 20% (and not 18.2%).

- Action 17 - “The Department of Health will commission 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 audit will be repeated one year on to enable the learning disability programme board to assess what is happening.”¹⁶

Census 2013 and the subsequent Learning Disabilities Census 2013 publication outputs were produced as a result of action 17. Action 17 therefore forms the publication’s driver.

5 Learning Disabilities Census 2013 objectives

Transforming care: A national response to Winterbourne View Hospital sets out “a programme of action to transform services so that people no longer live inappropriately in hospitals but are cared for in line with best practice, based on their individual needs...” (DH, 2012)¹⁷. To see this fundamental change come to fruition, the *Transforming Care* report has specified seven high-level actions (which are a summary of the 63 national actions), including:

- all current placements will be reviewed by 1 June 2013, and everyone inappropriately in hospital will move to community-based support as quickly as possible, and no later than 1 June 2014.¹⁸

Alongside the *Transforming Care* report, the DH published the Concordat, which, in agreement with external stakeholders, sets out “a shared commitment to transform services, and specific actions which individual partners will deliver...”. (DH, 2012)¹⁹

To “deliver the actions and commitments in *Transforming Care* and the Concordat to the timescales set out in those documents” (*Transforming Care Assurance Board*, 2014)²⁰, the *Transforming Care* programme was established. The programme was formed as a cross-system partnership made up of various organisations, including DH, NHS England, Local Government Association (LGA), CQC, Health Education England and Association of Directors of Adult Social Services (ADASS)²¹.

The Census 2013 publication is **supporting** the work of the *Transforming Care* programme by providing census-based information to **enable** commissioners and service providers to:

- review patients who have long lengths of stay and better understand their resettlement needs
- reduce lengths of stay in hospitals
- place patients in hospital settings and sites that are closer to their home
- transfer patients to appropriate settings, based on individual needs and wishes.

² The 63 national actions are NOT the same as the *Programme of Action* (the *Programme of Action* relates to the Concordat).

6 Publication uses

This section describes how identified stakeholders have used the Census 2013 publication outputs and, where appropriate, the Census's underlying data. It is not possible to engage with all users and exhaustively investigate all uses, but those identified are described below.

6.1 Department of Health (DH) – Winterbourne View: Transforming Care One Year On report

In 2013, the DH published the follow-up report to its *Transforming Care* report - *Winterbourne View: Transforming Care One Year On*²². Certain areas of the follow-up report were informed by the Census 2013 publication outputs. These were:

- the *One Year On* report highlighted some of the key issues described in the Census 2013 publication outputs, such as 60% of patients having a hospital stay of one year or more²³ and how these, in combination with other measures, will be tracked to monitor progress²⁴ against the aims and actions of *Transforming Care* and accompanying *Concordat*.
- the *One Year On* report identified data quality issues at provider-level, including issues highlighted in Census 2013, such as the unavailability of a valid residential postcode for 28% of patients²⁴, and how these issues need to be resolved, with the Census data expected to contribute to improvements in data quality²⁵.
- the *One Year On* report identified five key short-term actions to accelerate progress on the *Concordat: Programme of Action*. The Census 2013, in conjunction with the Joint Health and Social Care Self Assessment Framework³, was used to form point four of the action plan – “establish key performance indicators, using data from the Single Assessment Framework and the census”²⁶. A draft set of KPIs, which includes additional data sources, such as the mental health learning disabilities data set, has been developed to deliver this action.
- the *One Year On* report highlighted how the mismatch in Clinical Commissioning Group (CCG) CCG/NHS England registers and the numbers included in the census needed to be bridged, with the aim of ensuring that all service users have care plans²⁷ and commissioners are aware of who they are actually commissioning for²⁸. This issue is described in more detail in [section 6.3](#).

Quote

“The Learning Disability Census has given the Department of Health and its partners a much better understanding of the numbers of people with learning disabilities or autism in mental health hospitals and the care they are getting. We can use this to inform our work on moving people out of inpatient care into community based care where that is appropriate for them.”

Zawar Patel, Policy lead, Learning Disability, DH

³ Although the Concordat refers to the 'Single Assessment Framework', in practice it refers to the 'Joint Health and Social Care Self Assessment Framework'

6.2 Joint Improvement Programme

In line with action 13¹⁶ of the of the *Transforming care: A national response to Winterbourne View Hospital*, the Joint Improvement Programme (JIP) was established, with the aim of providing “leadership and support to the transformation of services locally” (Local Government Association, 2014)^{29 16}. The JIP, which completed its programme of work on 31 March 2015, was funded by DH as a two year programme and was jointly led by the LGA and NHS England.

The JIP has used the Census 2013, to inform two key activities.

- Provide targeted support to local areas⁴, including those with high inpatient numbers - the JIP has provided a range of ‘supported improvement’ options for local areas. This included more intensive work with 34 areas, through an in-depth review process (IDR)³⁰.

The 34 areas included in the IDR were approached to work in partnership with the JIP, based on an understanding of key issues and support needs, including an analysis of the numbers of people falling within the remit of the Transforming Care programme (i.e. numbers in inpatient care who are the responsibility of individual areas). This analysis was based on information available from the Census 2013 and NHS England data outputs.

- Specific JIP activities, including work with the Ministry of Justice (MoJ) – under part 3 of the Mental Health Act 1983³¹, a person can be diverted from the criminal justice system into inpatient settings, and may also have a MoJ restriction order/direction added to their section. The order has the effect of a person not being able to be discharged from inpatient care without the agreement of the MoJ. On census day 2013:
 - 613 of the 3,250 people in Census 2013 were ‘restricted patients’ in inpatient settings due to a diversion from the criminal justice system and an MoJ restriction order. These patients were detained under section 37 (with section 41 restrictions), section 47 (with section 49 restrictions) and section 48 (with section 49 restrictions) of the Mental Health Act 1983³².

The Census 2013 data and Assuring Transformation collection’s commissioner-based data is helping to inform work with the MoJ by looking at this group in more detail and enhance understanding of any issues that may be preventing or delaying some people from moving out of inpatient care and into community-based settings.

Related to this area, Glover and Brown (2015) published a journal article, which uses the Census 2013 as the key data source, to describe “the characteristics of individuals with intellectual disability in psychiatric hospitals in England who have been referred from the courts following charge or conviction for imprisonable offences.”³³

⁴ Local areas have been defined by the JIP as Health and Wellbeing Board areas or upper tier local authorities: Local Government Association (LGA), 2014. *Support to local areas* [Online] Available at: http://www.local.gov.uk/place-i-call-home/-/journal_content/56/10180/5615915/ARTICLE [Accessed 10 December 2014]

6.3 NHS England - Assuring Transformation collection

One of the key actions specified in the *Concordat: Programme of Action* is:

- Health and care commissioners will review all current hospital placements and support everyone inappropriately placed in hospital to move to community-based support as quickly as possible and no later than 1 June 2014.³⁴

The Assuring Transformation (AT) collection, which gathers data from NHS commissioners³⁵, was set up to provide assurance that the aforementioned action had been implemented and that people admitted after the *Transforming care: A national response to Winterbourne View Hospital* report were being actively reviewed. To January 2015, the AT collection was operated by NHS England, but, since then, has been migrated to HSCIC.

The analysis from the first AT collection, which reflected the position as at 31 December 2013, was published by NHS England in March 2014³⁶. Since then five quarter-end and four month-end analytical outputs have been published, with the most recent output concerning month-end 31 May 2015.^{37 38} The Census 2013 and AT's March 2014 collection data sets have been compared to identify trends and differences. One of the key findings has been the difference in patient numbers. The number of patients in the AT collection for quarter ending 31 March 2014 was 2,615, whereas the Census 2013 reported 635 more patients. To better understand the reasons for this variance, NHS England and HSCIC implemented the following changes:

- HSCIC introduced a new question to the Census 2014 to establish whether the variance in patient numbers between Census 2013 and AT data sets is because of the AT collection gathering data from NHS commissioners only. This new question was set out as:

Q48a. Which Commissioner, other organisation or individual is paying for the cost of care?

Answer list: 1 - NHS CCG, 2 - NHS England (Specialist Commissioning), 3 - Other NHS Commissioner outside England, 4 - Other NHS provider, 5 - Pooled budget, 6 - Local Authority, 7 - Private Funding, 8 - Non UK Commissioning.

- The AT collection has been migrated to HSCIC and is supported by a memorandum of understanding (MoU). The MoU states that HSCIC will undertake a detailed analysis of Census 2014 and AT's September 2014 collection, in order to better understand where the differences in patient numbers occur. NHS England will use this analysis to work with local commissioners (e.g. CCGs) to understand the reasons for the differences and identify and rectify any under-reporting issues.

The short-term aim of the comparison exercise is to create consistency across the Census and AT data sets and improve the completeness of the AT collection. The longer term aim, which supports action 42 of the *Transforming Care* report³⁹, is to ensure that local commissioners develop discharge plans in consultation with all key stakeholders, especially local service providers (e.g. local authorities), to reduce unwarranted inpatient stay.

Quote

“The Learning Disabilities Census data is invaluable in improving the data quality of the Assuring Transformation data as we use both sets of data to ensure we have captured all inpatients. We use the data to work with commissioners to ensure that they are all actively involved in preparing discharge plans for people with learning disabilities, so that people can be supported in their own homes, not in hospitals.”

Hazel Watson, Head of Mental Health and Learning Disabilities, NHS England

6.4 Public Health England

Public Health England (PHE) used the Census 2013 data and the 2010 Count Me In Census to inform trend analysis and identify new findings. In particular, the Census 2013 data was used to explore various elements, such as spread of distance of hospital from home for children and young people, prevalence of inpatient care for children and young people across regions, factors associated with adverse events and factors associated with longer lengths of hospital stay. Examples of factors identified with the latter include:

- patients admitted to wards that are 10km or more away from their home
- patients admitted to high security wards.

Using this analysis, PHE is aiming to produce and publish a report that presents the findings of their Census 2013 data analysis in mid-2015.

Glover and Brown (2015) published a journal article, which uses the Count me In Census and the Learning Disabilities Census 2013 as its key data sources, to “shed light on the trend in use of in-patient psychiatric care for people with learning disability or autism...and to consider the implications of the detailed trends for future care for this group”.⁴⁰

Quote

“The census has provided some key insights into the current numbers of people with learning disability or autism who are receiving mental healthcare at public expense. An increasing proportion of these are in private sector hospitals that do not currently report in the standard systems for NHS funded care. Without a census of this type, these people, on whom very large sums of public money are being spent, are not visible. If we are to meet the minister’s challenge in Transforming Care to resettle those that should not be in hospital to their home communities, this type of information is essential. ”

Gyles Glover, Co-director, Learning Disabilities Team, PHE

6.5 The Challenging Behaviour Foundation

The Challenging Behaviour Foundation (CBF) is a charitable organisation providing information and support to families of children and adults with severe learning disabilities who display behaviour described as challenging.

In 2014, the CBF, in partnership with Council for Disabled Children (CDC), commenced work on the Early Intervention Project (EIP), which is a three year project aimed at

facilitating improved early intervention for children with severe learning disabilities whose behaviours challenge⁴¹. The EIP has used the Census 2013 data to inform two activities:

1. Publish an evidence-based case for better early intervention – using data from Census 2013 and other sources, the EIP published the *Early intervention for children with learning disabilities whose behaviours challenge* (Nov 2014)⁴² briefing paper and the accompanying *Children with learning disabilities whose behaviours challenge, What do we know from national data? Nov 2014*⁴³ data supplement. The purpose of these outputs was to present (with recommendations) an evidence-based case for early intervention by:
 - drawing together the evidence for early intervention approaches for children with learning disabilities who display behaviour described as challenging⁴⁴
 - analysing all available national data for children with learning disabilities who display behaviour described as challenging⁴⁵.
2. Engage with the Children's Health and Wellbeing Partnership to increase the focus on children and young people (who are in inpatient settings) – the Children's Health and Wellbeing Partnership provides national leadership for the improvement of outcomes for children and young people. The EIP engaged with the Children's Health and Wellbeing Partnership board to present the case for a joined up approach for children and young people with learning disabilities who display behaviour described as challenging. This included proposing educational sector involvement in the review of care arrangements for children and young people in inpatient settings. The engagement exercise used the briefing paper, data supplement and Census 2014 data to evidence the case for a joined up approach.

As a result of the engagement, NHS England is now working with Department for Education (DfE) and special education needs and disabilities (SEND) advisors to identify relevant input from local education services into the Care and Treatment Review (CTR) programme for children with learning disabilities who are based in Acute Treatment Units (ATUs).

CTR is an NHS England programme, which commenced in late-2014, and, under the programme, independent expert advisers establish whether a person with learning disabilities needs to be in an inpatient setting and, for cases where care and treatment needs exist, why such needs cannot be met in the community⁴⁶.

As an additional output from the engagement exercise, the members of the Children's Health and Wellbeing Partnership are now working together with the EIP in preventing admissions of children and young people to ATUs.

Quote

“The Learning Disability Census has provided richer data than was previously available about people with learning disabilities in NHS funded inpatient settings. Reliable data about where people are and what they are experiencing is the first step towards developing more appropriate support and care close to home”

Jacqui Shurlock, Early Intervention Project Manager, CBF

6.6 Mencap

Mencap is a charity, which works in partnership with people with learning disabilities to change laws and services, challenge prejudice and directly support thousands of people (with learning disabilities) to live their lives as they choose.⁴⁷ Mencap has used the Census 2013 and Census 2014 publication outputs to inform the following activities:

- raise awareness and profile of numbers of people in inpatient settings – Mencap and CBF have collaboratively produced analytical outputs, in the form of one page information graphics ('infographics'), to make the Census 2013 and Census 2014 findings more accessible to members of public, journalists and other stakeholders. The key purpose of this is to make stakeholders aware of the changes that are still required to improve services for people with learning disabilities.
- campaign for better services - Mencap has used the Census 2013 and Census 2014 data to help people with learning disabilities and their families campaign for better services. It has done this by, for example, producing a web page on their website encouraging people with learning disabilities and their families to contact their local health and wellbeing boards or their learning disability partnership boards and using the Census 2013 and Census 2014 data as evidence to support the message that changes are still required to transform services.
- brief the House of Commons Public Accounts Committee (PAC), which held two evidence sessions on *Care services for people with learning disabilities and challenging behaviour* on 9 February 2015⁴⁸ - Mencap used the Census 2013 and Census 2014 data to brief the PAC on the provision of services for patients with learning disabilities and challenging behaviour. The first PAC session was with charity representatives, which included CBF, and the subsequent session was with officials who had responsibility in delivering the Transforming Care programme. The aim of these sessions was to establish what progress had been made in transforming services for people with learning disabilities since the release of the 2012 *Transforming Care* report and the accompanying *Concordat*.

Quote

"We have found the Learning Disabilities Census very useful. It provides important information about people with learning disabilities and behaviour that challenges in inpatient units, including length of stay, use of medication and restrictive practices. We have used it to raise public awareness about the experience of people with learning disabilities and help drive much needed change"

Dan Scorer, Head of Policy, Research & Public Affairs, Mencap

6.7 Care Quality Commission

Care Quality Commission (CQC), the independent regulator that inspects health and social care services in England⁴⁹, received a Census 2013-based data set (in pseudonymised form) in December 2013. This processed data was used to feed into CQC's new inspection approach, with commenced in February 2014 for specialist mental health providers.

Under phase one of the new inspection approach ('preparing for an inspection'), CQC produces a data pack for each inspection. The data packs contain various sets of data to inform the makeup of the inspection team and the key areas of focus for the inspection. The Census 2013 data is only used to aid a provider's inspection if the data meets specific inclusion criteria. One of the key elements of these criteria is the requirement to have a minimum number of service users accessing inpatient facilities, in order that patient confidentiality is preserved during reporting.

Between 1 February 2014 and 31 January 2015, CQC inspected 14 healthcare organisations that provided inpatient facilities for learning disabled patients. The application of the learning disabilities census criteria meant Census 2013 data could only be used to inform 3 inspections. Of the remaining 11, 10 inspections (providers) did not meet the criteria due to patient confidentiality preservation issues and 1 inspection was hindered by time constraints. The three inspections the Census 2013 data did inform were as follows:

- Calderstones Partnership Foundation Trust – this inspection⁵⁰ commenced in July 2014 and the inspection's data pack contained a small number of Census 2013 measures, such as legal status of patient at admission and source of referral. Other metrics derived from the Census 2013 data, such as consent status and reported incidents of self-harm, were included in supporting material.
- St Andrew's Healthcare – this inspection⁵¹ commenced in September 2014, but Census 2013 data was considered for the inspection's data pack, although, Census 2013-related metrics were included in supporting material.
- Tees, Esk and Wear Valley NHS Foundation Trust – this inspection commenced in late-January 2015 and the inspection's data pack contained various Census 2013 measures, such as legal status of patient at admission, percentage of patients by ward type and number of patients by care plan details.

The CQC highly values the learning disabilities census data, as, at present, it is the only source of national and comparable information available that helps the regulator assess how well independent service providers are delivering services for patients with learning disabilities. Furthermore, where an inspection is for a provider that specialises in learning disability services, such as the Calderstones Partnership Foundation Trust, the Census 2013 data provides a strong picture of the care provided.

Quote

"CQC is able to use the Learning Disabilities Census data as part of our monitoring data set. The data is the most reliable information we have regarding the number of patients in the system at the time of census, duration of stay and a snapshot of quality and safety of provision"

Alan Rosenbach, Strategy lead, CQC; and

Giovanna Polato, Team leader – Intelligence: Mental Health, Learning Disabilities & Community services, CQC

7 Census 2013 vs Census 2014 comparison assessment

In January 2015, DH published *Winterbourne View: Transforming Care Two Years On*⁵². The report, which was partly informed by Census 2013 and Census 2014, states that “two years on since Transforming Care was published, it is clear from this report that whilst we have made some progress, the system has not delivered what we set out to achieve.”⁵³

The findings presented in this case study strongly correlate with the findings of *Winterbourne View: Transforming Care Two Years On*. A review of a selection of measures, as based on Census 2013 and Census 2014 data sets, and which are presented in the table below, show that service delivery has stayed fairly static between the two years.

No.	Measure	Census 2013	Census 2014 ⁵	change ⁶
1	Inpatient cohort size (i.e. number meeting the LD census criteria) ⁵⁴	3,250 (104 provider organisations)	3,230 (92 provider organisations)	-1%
2	Percentage of inpatients aged under 18 ⁵⁵	5%	5%	+0%
3	Mean length of stay ⁵⁶	1,065 days	1,034 days	-3%
4	Percentage of inpatients with ward stay between 5 years and 10 years (with current provider) ⁵⁷	12%	12%	+0%
5	Percentage of inpatients staying in wards located between 50km and 100km from their home address ⁵⁸	20%	20%	+0%
6	Percentage of inpatients staying in wards located 100km or more from their home address ⁵⁹	20%	19%	-1%
7	Percentage of males on a mixed sex ward ⁶⁰	17%	15%	-2%
8	Percentage of females on a mixed sex ward ⁶¹	11%	11%	+0%
9	Percentage of patients for whom a valid home postcode could not be supplied by provider	28% ⁶²	28% ⁶³	N/A
10	Percentage of inpatients with an unknown 'ZZ99' residential postcode or invalid residential postcode (post-data matching exercise with HSCIC's Personal Demographics Service)	2% ⁶⁴	6% ⁶⁵	N/A
11	Percentage of inpatients currently receiving active treatment plan, discharge plan not in place ⁶⁶	46%	37%	-9%
12	Percentage of inpatients experiencing a delayed transfer of care ⁶⁷	5%	5%	+0%

⁵ Rounded to the nearest 5 (Census 2013 values are NOT rounded to nearest 5)

⁶ The % point change has only been calculated for the purposes of this case study. The % point change value has not been included in the Census 2014 publication.

No.	Measure	Census 2013	Census 2014 ⁵	change ⁶
13	Percentage of inpatients receiving care in high security ward ⁶⁸	2%	2%	+0%
14	Percentage of incidents recorded in the 3 months prior to census date (denominator is total number of inpatients) ⁶⁹	42%	45%	+3%
15	Percentage patients who experienced one or more incident (self-harm, accidents, physically assaulted, restraint or seclusion) in the three months prior to census date ⁷⁰	58%	55%	+3%
16	Percentage of inpatients being detained under the Mental Health Act 1983, on day of census ⁷¹	78%	80%	+2%
17	Percentage of inpatients being detained under the Mental Health Act 1983 and with a restriction order, on day of census ⁷²	19%	20%	+1%
18	Percentage of patients receiving antipsychotic medication ⁷³	68%	73%	+5%
19	Number of patients receiving inpatient care at time of both census collections ⁷⁴	1,975		N/A
20	Number of patients receiving continuous inpatient care between both census collections ⁷⁵	1,830		

8 Improved outcomes and measurable benefits

In this section the terms 'improvement(s)' and 'measurable benefit(s)' are used interchangeably.

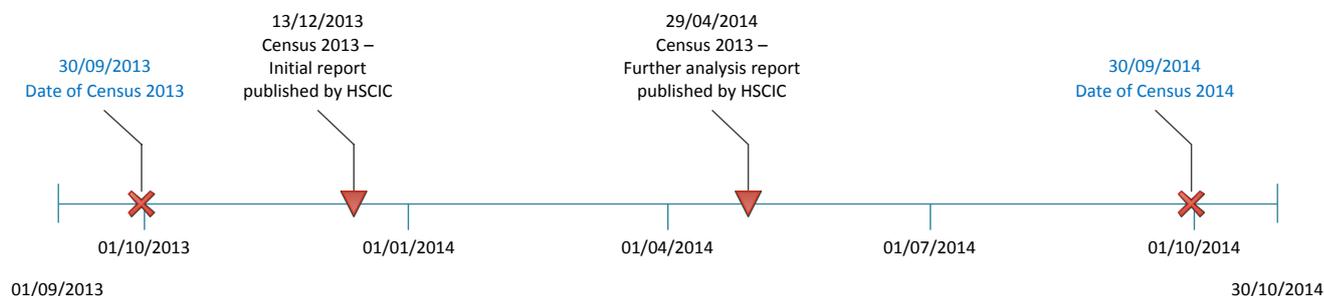
8.1 New findings into care patterns

The Census 2013 has provided a detailed understanding on the patterns of care for people with learning disabilities (which includes people with autistic spectrum disorders and/or behaviour that challenges). This insight would not have been viable had the Census not been performed. It is therefore important to recognise that Census 2013 (and Census 2014) has given stakeholders the capability to start improving service delivery and outcomes, with the ultimate aim of benefiting patients. Examples of how stakeholders are using the Census 2013 capability to inform service delivery have already been described in [section 6](#).

8.2 Constraining factors affecting delivery of improved outcomes and measurable benefits

Two key factors have possibly constrained stakeholders in using the Census 2013 data to generate marked improvements, especially with regards to inpatient stay, for Census 2014:

1. Timeline of events - the timeline of events, as shown below, illustrates that stakeholders only had a nine month window within which to analyse the first Census 2013 publication output and subsequently produce and implement action plans to generate improvements for Census 2014.



2. Patient characteristics and care needs - the characteristics and health and social care needs of people with learning disabled patients (who are inpatients) creates challenges in delivering early improvements. Examples of such characteristics and needs include:

- high proportion of patients with high inpatient stay (e.g. inpatient stay of one year or more)
- the need to have detailed advanced planning to support long term care needs.

These factors meant that there was limited time for stakeholders to positively influence the 2014 Census. It is expected, though, that the uses of the Census 2013 and 2014 publication outputs, including those described in section 6, will show improvements in the coming year.

8.3 Improved outcome and measurable benefit contributed to

Due to the issues set out in section 8.2 (and, possibly, other factors, which have not been explored in this case study), the uses described in section 6 have contributed to one improved outcome and one corresponding measurable benefit. This is described in the table below.

Activity contributing to outcome and/or benefit	Improved outcome	Measurable benefit (i.e. improvement)
CQC using Census 2013 data to inform inspections	<p>CQC increasing the effectiveness of inspections, which, in turn, ensures:</p> <ul style="list-style-type: none"> • inspections are focused in the right areas • key issues are not overlooked during inspections 	<p>An increase in the number of inspections informed by Census 2013 data.</p> <ul style="list-style-type: none"> • To 31 January 2014 – 0 (because Census 2013 data unavailable) • 1 February 2014 to 31 January 2015 - 3 inspections

8.4 Measurable benefits realised through external activities

Based on the data table in [section 7](#), between Census 2013 and Census 2014, a marked improvement was realised in one area:

No.	Measure	2013 census	2014 census	% points change
11	Percentage of inpatients currently receiving active treatment plan, discharge plan not in place	46%	37%	-9%

The investigatory work undertaken for this case study has not been able to link any Census 2013 data uses to the improvement, so it is likely that the improvement has been initiated from sources other than the Census 2013 publications. Possible sources include:

- The definitional change that occurred in the measure's underlying question in Census 2014 – in both census collections, there was a question on 'Details of patient's care plan' (Q44c in Census 2014)⁷⁶. The question had 6 options in the answer list. The measure stated above is based on the percentage of providers selecting option 2 ('currently receiving active treatment plan, discharge plan not in place').

Between Census 2013 and Census 2014, option 1 of the answer list was revised from 'Currently not dischargeable because of mental illness' to 'Currently not dischargeable because of level of behaviour that presents a risk to the person or others, or mental illness' (options 2 – 6 retained the Census 2013 wording). It is possible that the change in option 1 may have resulted a change in how this question was answered (i.e. a decreased use of option 2).

- Activities NHS England has undertaken as a result of analysing the AT collection data.
- Efforts stakeholders have made in delivering the actions of the *Transforming care: A national response to Winterbourne View Hospital* and the accompanying *Concordat: Programme of Action*.

Since the improvement is likely to have resulted from non-Census 2013 uses, this improvement has not been referenced in [section 8.3](#).

9 Contributions

This case study had contributions from, and/or been reviewed by:

- Zawar Patel, Policy lead, Learning Disability, DH
- Kate Hardy, Senior Policy Manager, Transforming Care, DH
- Hazel Watson, Head of Mental Health and Learning Disabilities, NHS England
- Andy Tookey, Data & Information Lead, Learning Disability Programme, NHS England

- Jane Alltimes, Policy Adviser, Winterbourne View Joint Improvement Programme, LGA
- Gyles Glover, Co-director, Learning Disabilities Team, PHE
- Vivien Cooper, Chief Executive, CBF
- Jacqui Shurlock, Early Intervention Project Manager, CBF
- Bella Travis, Policy Lead, Mencap
- Dan Scorer, Head of Policy, Research & Public Affairs
- Giovanna Polato, Team leader – Intelligence: Mental Health, Learning Disabilities & Community Services, CQC
- Robert Cavalleri, Specialist Learning Disabilities Project Lead, HSCIC.
- Clare Burgon, Senior Information Analyst, Community and Mental Health Team, HSCIC

10 References

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