Findings from the Balance of Care / Continuing Care Census

Census held 31 March 2014

Publication date – 24 June 2014
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Introduction

This report presents findings from the Balance of Care/NHS Continuing Health Care census held on 31 March 2014. It is important to note that these data represent a snapshot of the position at a certain point in time. The figures do not present the total number of individuals who were in receipt of NHS Continuing Care over the whole year.

The census covers all patients whom clinicians have assessed to meet the criteria for NHS Continuing Health Care and certain other patients who did not meet the criteria for NHS Continuing Health Care but have been in hospital for over 1 year and for whom no estimated date of discharge has been set.

This report presents:

- summary age/gender information for Scotland, NHS Board of Treatment, Local Authority of Residence
- specialty, Length of Stay and Location of Care information

Previous censuses were held in September 2008, March and September 2009, March and September 2010, March 2011, March 2012 and March 2013. Following consultation with NHS Boards a decision was taken in 2011 to move the NHS Continuing Health Care census from bi-annual to an annual collection. Trend information presented in this publication is at the March census each year.

Link to tables and charts on the ISD Website - Link to NHS Continuing Health Care tables

NHS Continuing Health Care guidance

NHS Continuing Health Care is a package of health care provided and solely funded by the NHS. Patients normally receive NHS Continuing Health Care in a hospital ward, hospice or a contracted inpatient bed within an independent sector provider e.g. Care Home. The NHS, and not the local authority or individual, pays the total cost of that care. NHS Continuing Health Care may be for prolonged periods but not necessarily for life and entitlement should be subject to regular review.

In February 2008, the Scottish Government issued revised guidance on NHS Continuing Health Care to NHS Boards in CEL 6(2008) (see link below).


The guidance indicates that continuing inpatient care should be provided where there is a need for ongoing and regular specialist clinical supervision of the patient as a result of:-

- the complexity, nature or intensity of the patient’s health needs, being the patient’s medical, nursing and other clinical needs overall;
• the need for frequent, not easily predictable, clinical interventions;
• the need for routine use of specialist health care equipment or treatments which require the supervision of specialist NHS staff; or
• a rapidly degenerating or unstable condition requiring specialist medical or nursing supervision.

About the census

Until 2008 there was no method for identifying all patients who were receiving NHS Care that is on-going, non-acute care, delivered as an inpatient, and often over an extended period, either in hospital, hospice or care home. The census was introduced to gather information on these patients.

In June 2013, in response to concerns raised in the media regarding the application of the guidance contained in CEL 6(2008) by Health Boards in Scotland, the Cabinet Secretary for Health and Wellbeing commissioned an independent panel to review the delivery, monitoring and governance of NHS Continuing Healthcare in Scotland.

Since this census was carried out an independent review of NHS Continuing Care has been published, commissioned by the Scottish Government (http://www.scotland.gov.uk/Publications/2014/03/2480). This makes a number of recommendations about how this type of care is provided including recommendations about the data collection method. The Scottish Government have accepted the recommendations and committed to review the current guidance in time for implementation from April 2015. Therefore, this will be the final publication of the Continuing Care census under the current guidance and ISD will work with the Scottish Government on the best method to measure Continuing Care under the revised guidance.

Much of the concern of the review was in relation to the interpretation and implementation of the guidance by NHS Boards and their varying data collection methods. Whilst acknowledging the findings of the review it is our opinion that it is of value to release these data under National Statistics protocols since, as for previous years publications, they give the only nationally available picture of how Boards are interpreting the current guidance, albeit at a single census point within the year.

The data contained in this publication was collected prior to the publication of the Independent Review of NHS Continuing Healthcare.

Shifting the Balance of Care for Older People

The Scottish Government is committed to a shift in the balance of care to ensure that older people are cared for in their own homes or in a homely setting in the community, wherever possible. Information collected by the Scottish Government on Home Care Services and Care Homes will combine with these data to monitor shifts in the balance of care. Data from the Continuing Care census feeds into the Scotland Performs indicator to “Increase
the percentage of people aged 65 and over with high levels of care needs who are cared for at home” - http://www.scotland.gov.uk/About/scotPerforms/indicator.

Since 2008 there has been a steady increase in the proportion of people aged 65 and over receiving personal care at home from 57.1% in 2008 to 61.9% in 2013. This information is published by Scotland Performs and can be found here: http://www.scotland.gov.uk/About/Performance/scotPerforms/indicator/careneeds

Related Health and Social Care Information

ISD publishes other information that helps to measure the shift in the balance of care to ensure that older people are cared for in their own homes or in a homely setting in the community, wherever possible. The Scottish Care Home Census (SCHC) publication looks at the provision of care home places throughout Scotland and for individual local authorities. Some patients may receive Continuing Care in a contracted inpatient bed within a care home and the SCHC publication can be used to provide further information about patient characteristics in care homes.

Trend data is available from March 2000. A link to the latest published information can be found here:
http://www.isdscotland.org/Health-Topics/Health-and-Social-Community-Care/Care-Homes/Census/

For most patients, following completion of health and social care assessments, the necessary care, support and accommodation arrangements are put in place in the community without any delay in the patient's safe and appropriate discharge from hospital. A ‘delayed discharge’ is a hospital inpatient who has been judged clinically ready for discharge by the responsible clinician, in consultation with all agencies involved in planning the patient’s discharge, who continues to occupy a bed beyond the ready for discharge date. These patients are clinically ready to move on to a more appropriate care setting either within or out with the NHS e.g. patient’s home, care home etc. A small number of patients who appear on the Balance of Care / Continuing Care census may also be delayed discharges. Further information can be found at the following link:
http://www.isdscotland.org/Health-Topics/Health-and-Social-Community-Care/Delayed-Discharges/

The Scottish Government publishes other information relating to service provision for older people and this can be found at the following website:
http://www.scotland.gov.uk/Topics/Statistics/Browse/Health/
Data Quality

ISD carries out a number of checks on the census data received to ensure the information is as complete and accurate as possible. These checks include: using National Records Scotland (NRS) deaths information to remove any patients who have died since the last census; querying missing information, such as CHI and location code; and asking for clarification around any unusual trends e.g. a large increase or decrease in patients. A full list of the data checks carried out by ISD can be found at the following link: http://www.isdscotland.org/Health-Topics/Health-and-Social-Community-Care/NHS-Continuing-Care/Census-Documentation/.

The following points should be considered prior to drawing conclusions from the data presented.

- **Comparing data between NHS Boards/Local Authorities**
  As described in the findings of the Independent Review of NHS Continuing Care the provision of NHS Continuing Health Care was shown to vary across NHS Boards in Scotland, therefore, comparisons of figures should take this into account when interpreting across NHS Boards.

- **Comparisons between years**
  The latest figures as at 31 March 2014 can be treated as being broadly comparable to previous years’ census points.

- **Continuing Care Census Guidance**
  NHS Boards are asked to provide information as per the Balance of Care/Continuing Care Definitions and Data Recording manual which can be found at the following link: http://www.isdscotland.org/Health-Topics/Health-and-Social-Community-Care/NHS-Continuing-Care/NHS-Continuing-Care-Census-Guidance-updated-March-2014_final.pdf

Acknowledgements

Thanks go to NHS Boards for their continued help in collating these data from local services and for their assistance in data validation.
Key points

Patients who are receiving NHS Continuing Health Care as a result of a decision made under the terms of the NHS Continuing Health Care guidance are recorded as Category A patients.

- At March 2014, 1,634 Category A patients were reported as receiving NHS Continuing Health Care. The figures have shown a decrease of 5% (77 patients) from the March 2013 census.
- At March 2014, 78% of Category A patients were aged 65 years and over.

Patients who do not specifically meet the criteria for NHS Continuing Health Care but who have been in hospital for over one year and for whom no estimated date of discharge has been set are recorded as Category B patients.

- At March 2014, there were 521 patients who did not meet the criteria for NHS Continuing Health Care but who have been in hospital for over one year and for whom no estimated date of discharge has been set (Category B); this is a decrease of 7% (41 patients) from last year.
- 21% of Category B patients were aged 65 years and over.
Results and Commentary

Number of Category A and Category B patients

- Overall there were 2,155 patients reported in the Balance of Care / Continuing Care census at March 2014 which is a decrease in the numbers reported at March 2013 (2,273 patients).
- Of these, 76% were classed as Category A patients who were receiving NHS Continuing Health Care and 24% were classed as Category B patients who did not specifically meet the criteria for NHS Continuing Health Care but had been in hospital for more than a year and no estimated date of discharge had been set.
- 1,634 patients were reported as Category A at March 2014, compared to 1,711 at March 2013.
- 521 patients were reported as Category B at March 2014, compared to 562 at March 2013.
- Figure 1 shows a decrease in Category A patients over time and an overall decrease of 40% since March 2009.

Figure 1 Number of patients in Scotland reported in the Balance of Care / Continuing Care Census, March 2009 to March 2014

Category A: Patients who are receiving NHS Continuing Health Care as a result of a decision made under the terms of the guidance detailed on page 3 of this report.

Category B: Patients not eligible to receive NHS Continuing Health Care but who have been in hospital for over a year and have no date of discharge set.
Figure 2 shows that there was a fall in the number of NHS Continuing Health Care (Category A) patients in 9 NHS Health Boards between March 2013 and March 2014. It should be noted that the decrease in Category A patients in Western Isles is attributable to new local procedures adopted in 2013/14; all Western Isles patients for this census fall under Category B. Shetland had no Category A patients in 2013 and one in 2014, while Orkney had no Category A patients in either year. The number of Category A patients at Dumfries and Galloway rose from two to four.

Between the March 2013 and March 2014 censuses, for reasons described previously, there was an increase of 21 Category B patients in Western Isles. There was however a decrease in Category B patients in 7 NHS Boards, leading to an overall decrease of 41 Category B patients in Scotland.
Tracking patients between census points

- Figure 3 tracks the movement of patients between the March 2013 and 2014 censuses. The tables below present details on whether patients were reported only in the March 2013 census, changed categories between censuses, were reported in all censuses under the same category or were new to the census in March 2014.

Figure 3 Tracking patients between census points

<table>
<thead>
<tr>
<th>Continuing Care patients (with valid CHI number)$^1$ in 2014</th>
<th>Category A</th>
<th>Category B</th>
<th>Not in census</th>
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<tr>
<td><strong>Continuing Care patients (with valid CHI number)$^1$ in 2013</strong></td>
<td></td>
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<tr>
<td>Category A</td>
<td>993</td>
<td>69</td>
<td>632</td>
<td>1694</td>
</tr>
<tr>
<td>Category B</td>
<td>49</td>
<td>281</td>
<td>231</td>
<td>561</td>
</tr>
<tr>
<td>Not in census</td>
<td>577</td>
<td>167</td>
<td></td>
<td>744</td>
</tr>
<tr>
<td><strong>Total</strong></td>
<td>1619</td>
<td>517</td>
<td></td>
<td>2136</td>
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</table>

$^1$ The March 2013 and 2014 censuses were compared using the patient Community Health Index (CHI) number and only those with a valid CHI are included in the matching process.

- There were 993 Category A patients and 281 Category B patients who were reported in both the 2013 and 2014 censuses.
- For Category A patients, 37% of patients who were reported in the March 2013 census did not appear in the March 2014 census and 34% of patients were new to the census in March 2014.
- For Category B patients, 41% of patients who were reported in the March 2013 census did not appear in the March 2014 census and 30% of patients were new to the census in March 2014.
**Age and gender**

- At March 2014, 75% of Category B patients were male, which is a slight increase from the percentage reported at March 2013.
- The majority (78%) of Category A patients were aged 65 years and over. In contrast only 21% of Category B patients were 65 years and over at the census date.
- Figures 4 & 5 present data by age group and gender at the March 2014 census:
  - Compared to males, there is a relatively higher proportion of female Category A patients in the older age groups.
  - For Category B patients, when compared to females, the distribution of males is more concentrated at the younger end of the age spectrum. 48% of all male Category B patients are aged between 18 and 44 while 17% are aged 65 and over. By comparison, 31% of all female Category B patients are aged between 18 and 44 while 33% are aged 65 and over.

**Figure 4 Percentage of Category A patients by age group, March 2014**

![Figure 4](image1.png)

**Figure 5 Percentage of Category B patients by age group, March 2014**

![Figure 5](image2.png)
Figure 6 shows the Scottish rate for Category A patients at March 2014 by Health Board. The 1,634 patients reported as receiving NHS Continuing Health Care at March 2014, corresponds to a Scottish rate of 20 patients per 100,000 Scotland population.

There is a significant variation in the rate for each NHS Board. NHS Greater Glasgow and Clyde and NHS Lothian have the highest rates of Category A patients per 100,000 population, at 35 and 31 respectively, compared with 2 patients per 100,000 population in NHS Dumfries & Galloway.

Figure 6 Number of Category A patients expressed as rate per 100,000 Scotland population, March 2014

1 Due to new local procedures adopted in 2013/14, continuing care patients in Western Isles previously reported as category A have been revised to category B.
Specialty, Location of Care and Length of Stay for Category A patients

- The majority of all Category A patients were in either Psychiatry of Old Age (42%, 681 patients) or Geriatric Medicine (36%, 594 patients) specialties at March 2014.
- Of the 1,634 Category A patients, 1,235 (76%) were resident in hospital, 385 (24%) in a Care Home and 14 (1%) in other locations.
- The reported fall in the number of Category A patients is a consequence of a decrease in the number of patients in Geriatric Medicine and General Psychiatry specialties in hospitals; there has only been a small drop in the care home population for these specialties.
- The length of stay varies between specialties. Scotland level figures are dominated by three groups: Psychiatry of Old Age, Geriatric Medicine and General Psychiatry, each of which has a different profile. Figure 7 shows the variation in length of stay for each specialty.

Figure 7 Length of Stay and Specialty for Category A patients, March 2014

1 Specialties not shown where length of stay is based on 5 patients or less.
For Category B patients, the most common specialties were General Psychiatry (34%, 178 patients), Forensic Psychiatry (31%, 163 patients) and Learning Disability (16%, 83 patients).

Of the 521 Category B patients, 507 (97%) were resident in hospital and 12 patients (2%) were located in care homes (including NHS Beds on a contracted basis).

Figure 8 shows the variation in length of stay for Category B patients for each specialty.

Figure 8 Length of Stay and Specialty for Category B patients, March 2014

1 Specialties not shown where length of stay is based on 5 patients or less.
Glossary

Category A
Patients who are receiving NHS Continuing Health Care as a result of a decision made under the terms of the NHS Continuing Health Care guidance (see page 3). Note that although NHS Continuing Health Care may be provided in a hospital ward it may also be provided on a contractual basis in a hospice or care home.

Category B
Patients who do not specifically meet the criteria for NHS Continuing Health Care but who have been in hospital for over one year and for whom no estimated date of discharge has been set.

NHS Continuing Health Care guidance
NHS Continuing Health Care is a package of health care provided and solely funded by the NHS. Patients normally receive NHS Continuing Health Care in a hospital ward, hospice or a contracted inpatient bed within an independent sector provider e.g. Care Home. The NHS, and not the local authority or individual, pays the total cost of that care. NHS Continuing Health Care may be for prolonged periods but not necessarily for life and entitlement should be subject to regular review.

In February 2008, the Scottish Government issued revised guidance on NHS Continuing Health Care to NHS Boards (see link below).


The guidance indicates that continuing inpatient care should be provided where there is a need for ongoing and regular specialist clinical supervision of the patient as a result of:-

(a) the complexity, nature or intensity of the patient’s health needs, being the patient’s medical, nursing and other clinical needs overall;
(b) the need for frequent, not easily predictable, clinical interventions;
(c) the need for routine use of specialist health care equipment or treatments which require the supervision of specialist NHS staff; or
(d) a rapidly degenerating or unstable condition requiring specialist medical or nursing supervision.

In June 2013, in response to concerns raised in the media regarding the application of the guidance contained in CEL 6(2008) by Health Boards in Scotland, the Cabinet Secretary for Health and Wellbeing commissioned an independent panel to review the delivery, monitoring and governance of NHS Continuing Healthcare in Scotland.

The panel concluded their investigations in January 2014, and this report details their findings: http://www.scotland.gov.uk/Publications/2014/03/2480
The Scottish Government will issue updated guidance for NHS Continuing Health Care from April 2015.

**Standardisation**

The use of standardisation allows for fairer comparison between study populations with differing age/sex structures. A directly age/sex standardised rate is a theoretical rate, based on the rates observed in the study populations within the chosen age/sex groups, and the relative frequencies of these age/sex groups within a standard population. The replacement of the age/sex group frequencies in the study populations with those in the standard population gives the rates that would be observed if the age structure of the study populations were the same as that of the standard population.

Historically the data presented in this census report has used the European Standard population however this is a younger population than the Scottish population and the interest in this census is mainly older people. The data in this publication have been age/sex standardised to the Scottish population.
## List of Tables

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<td>Table 11</td>
<td>Location of care for Category B patients by Specialty.</td>
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Contact
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Further Information
Further information can be found on the ISD website

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Appendix

A1 – Background Information

The patients who were included in the census were:

Category A: Patients who are receiving NHS Continuing Health Care as a result of a decision made under the terms of the guidance referred to on pages 3 of this report. Note that although NHS Continuing Health Care may be provided in a hospital ward it may also be provided on a contractual basis in a hospice or care home.

Category B: Patients who do not specifically meet the criteria for NHS Continuing Health Care but who have been in hospital for over one year and for whom no estimated date of discharge has been set.

The following data items were collected:

- Location Code
- Location Name
- CHI Number
- Patient Identifier (if CHI unavailable)
- Patient Name
- Gender
- Date of Birth
- Date of Admission
- Ethnicity
- Specialty
- Patient’s postcode of residence

NHS Boards were instructed to carry out the census on the 31st March 2014. However, if there was local benefit in undertaking the national census on a date other than the 31st March NHS Boards could select a date up to 3 calendar days prior to the census date.
## A2 – Publication Metadata (including revisions details)

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<td>Findings from the Balance of Care / Continuing Care Census</td>
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<td><strong>Description</strong></td>
<td>Annual publication presenting data on all patients whom clinicians had assessed to meet the criteria for NHS Continuing Health Care and certain other patients who did not meet the criteria for NHS Continuing Health Care but had been in hospital for over 1 year and for whom no estimated date of discharge had been set.</td>
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<td><strong>Date that data are acquired</strong></td>
<td>31 March 2014 (most recent census)</td>
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<td><strong>Release date</strong></td>
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<td><strong>Frequency</strong></td>
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<td><strong>Timeframe of data and timeliness</strong></td>
<td>Annual census as at 31st March. Information is published annually. No delays between data availability and processing of data for publication. In 2013, one area provided part of their data as at 13th May in order to tie in with other local reporting. These figures are included in this publication and relevant notes have been added to the tables.</td>
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<td><strong>Continuity of data</strong></td>
<td>To date, data have been gathered for 7 census points and there have been no major discontinuities of data. Within the publication, local authority of residence could not be presented until the 3rd Census due to lack of accurate recording of postcode of residence, this was noted in the relevant publication..</td>
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<td><strong>Revisions statement</strong></td>
<td>Previously published data are on occasion revised following comparison with more recent data received which highlight inconsistencies with historic data. These revisions are unplanned. It is likely that these revisions will continue until the census is more embedded into local practices. Examples of errors are wrong dates of admission, incorrect categorisation of patients (NHS continuing care vs. in hospital for over 1 year), postcode of institution instead of original residence of patient. Due to the length of time that some of these patients have been in hospital it has not always been possible to obtain original records and for this reason queries may still be included.</td>
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**publication**  | figures.
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**Concepts and definitions**  | A copy of the [Definitions and Data Recording](#) manual can be found on our website.
**Relevance and key uses of the statistics**  | Findings from the Census support the Scottish Government to monitor Shifting the Balance of long term care for older people and also to inform on the application of the NHS Continuing Health Care guidance. The data can be used by NHS Boards to monitor patients in receipt of NHS Continuing Care and also to highlight those patients who have been in hospital for over 1 year, to ensure that they are in the most appropriate care setting.
**Accuracy**  | Census data are subject to validation when data files are received by ISD. Validation reports are returned to NHS Boards for correction of data/verification of queries. Reported data are compared to previous Census figures.
**Completeness**  | As part of the validation process, NHS Boards are provided with numbers reported from each hospital/care home and Specialty. They are invited to review and amend as required. It is therefore assumed that data received is 100% complete.
**Comparability**  | There are currently no comparable/consistent sources of data available for UK comparison. Some patients may receive Continuing Care in a contracted inpatient bed within a care home and the Scottish Care Home Census publication could be used to provide further information about patient characteristics in care homes (see page 3 for further information).
**Accessibility**  | It is the policy of ISD Scotland to make its web sites and products accessible according to [published guidelines](#).
**Coherence and clarity**  | The publication includes sections on Introduction/background, data quality, key findings (including charts) and then tables.
**Value type and unit of measurement**  | Number, percentage and Scottish rate
**Disclosure**  | The [ISD protocol on Statistical Disclosure Protocol](#) is followed.
**Official Statistics designation**  | Official Statistics
**UK Statistics Authority Assessment**  | Designated as National Statistics By UKSA in November 2012
**Last published**  | 25th June 2013
**Next published**  |
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A3 – Early Access details (including Pre-Release Access)

Pre-Release Access
Under terms of the "Pre-Release Access to Official Statistics (Scotland) Order 2008", ISD are obliged to publish information on those receiving Pre-Release Access ("Pre-Release Access" refers to statistics in their final form prior to publication). The standard maximum Pre-Release Access is five working days. Shown below are details of those receiving standard Pre-Release Access and, separately, those receiving extended Pre-Release Access.

Standard Pre-Release Access:
- Scottish Government Health Department
- NHS Board Chief Executives
- NHS Board Communication leads

Extended Pre-Release Access
Extended Pre-Release Access of 8 working days is given to a small number of named individuals in the Scottish Government Health Department (Analytical Services Division). This Pre-Release Access is for the sole purpose of enabling that department to gain an understanding of the statistics prior to briefing others in Scottish Government (during the period of standard Pre-Release Access).

Scottish Government Health Department (Analytical Services Division)

Early Access for Management Information
These statistics will also have been made available to those who needed access to ‘management information’, ie as part of the delivery of health and care:

Policy Manager responsible for NHS Continuing Care and Delayed Discharges within the Primary & Community Care Directorate, Partnership Improvement & Outcomes Division at Scottish Government.

Early Access for Quality Assurance
These statistics will also have been made available to those who needed access to help quality assure the publication:

Policy Manager responsible for NHS Continuing Care and Delayed Discharges within the Primary & Community Care Directorate, Partnership Improvement & Outcomes Division at Scottish Government.
A4 – ISD and Official Statistics

About ISD

Scotland has some of the best health service data in the world combining high quality, consistency, national coverage and the ability to link data to allow patient based analysis and follow up.

Information Services Division (ISD) is a business operating unit of NHS National Services Scotland and has been in existence for over 40 years. We are an essential support service to NHSScotland and the Scottish Government and others, responsive to the needs of NHSScotland as the delivery of health and social care evolves.

Purpose: To deliver effective national and specialist intelligence services to improve the health and wellbeing of people in Scotland.

Mission: Better Information, Better Decisions, Better Health

Vision: To be a valued partner in improving health and wellbeing in Scotland by providing a world class intelligence service.

Official Statistics

Information Services Division (ISD) is the principal and authoritative source of statistics on health and care services in Scotland. ISD is designated by legislation as a producer of ‘Official Statistics’. Our official statistics publications are produced to a high professional standard and comply with the Code of Practice for Official Statistics. The Code of Practice is produced and monitored by the UK Statistics Authority which is independent of Government. Under the Code of Practice, the format, content and timing of statistics publications are the responsibility of professional staff working within ISD.

ISD’s statistical publications are currently classified as one of the following:

National Statistics (ie assessed by the UK Statistics Authority as complying with the Code of Practice)

National Statistics (ie legacy, still to be assessed by the UK Statistics Authority)

Official Statistics (ie still to be assessed by the UK Statistics Authority)

other (not Official Statistics)

Further information on ISD’s statistics, including compliance with the Code of Practice for Official Statistics, and on the UK Statistics Authority, is available on the ISD website.

The United Kingdom Statistics Authority has designated these statistics as National Statistics, in accordance with the Statistics and Registration Service Act 2007 and signifying compliance with the Code of Practice for Official Statistics. Designation can be broadly interpreted to mean that the statistics:

meet identified user needs;

are well explained and readily accessible;

are produced according to sound methods, and

are managed impartially and objectively in the public interest.

Once statistics have been designated as National Statistics it is a statutory requirement that the Code of Practice shall continue to be observed.