Acquired Brain Injury: The numbers behind the hidden disability

Methodology, injury categories and further notes
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Introduction to methodology

The figures presented here have been obtained using the Hospital Episode Statistics (HES) system in England and its equivalents elsewhere in the UK (see ‘Notes, Codes and categories’ sections of the data spreadsheets for further details). These systemically record all hospital admissions according to diagnosis.

Finished admission episodes (FAEs) have been used as these indicate one complete treatment period. One FAE may include several finished consultant episodes (FCEs) as the patient is referred to different consultants. Several diagnosis positions are recorded for patients in order to account for different conditions and injuries. The figures used in this study are for primary diagnosis in order to show those whose main condition is ABI. Of course, this will omit many others who sustain an ABI but whose brain injury is coded in a lower diagnostic position (this largely applies to head injuries).

Brain injuries have been identified using the International Classification of Disease version 10 (ICD-10) diagnosis codes. The work builds on previous studies by Professor Alan Tennant at the University of Leeds (Tennant, 2005[1]), which looked at admissions to hospitals in England for ICD-10 codes for head injury (codes S00 – S09). This work used the head injury codes as a proxy for traumatic brain injury (TBI), using the rationale that head injuries significant enough to warrant admission to hospital are highly likely to cause brain injury of at least minor severity.
There has been much debate about which head injury codes are appropriate for inclusion in studies of brain injury. Only code S06 (intracranial injury) specifically relates to brain injury and so some studies have focused entirely on this code or added others such as S02 (skull fractures) and S07 (crushing injuries of the head) (Chen and Colantonio, 2011). However, research has indicated that ignoring other types of head injury will omit many people with traumatic brain injuries (Martin et al, 2002). For this reason, Tennant’s work included all head injury codes.

The statistics presented here refined the analysis of traumatic brain injury further by omitting all those admitted for superficial head injuries (code S00), reasoning that long-term brain injuries would be rare in this group.

Other (often unpublished) work has attempted to identify other forms of ABI using ICD-10 codes. Because Headway supports people with all forms of ABI, we have taken the approach of using as wide-ranging a selection of codes as possible and identifying sub-sets of certain conditions where appropriate (i.e. malignant, benign and uncertain tumours).

Although the ICD-10 coding system generally categorises similar conditions together (i.e. I60-I69 for strokes), this isn’t always the case (i.e. meningitis, with different types in the A, B and G codes). Therefore, we have taken the approach of extensively searching all appropriate sections of the ICD-10 code list in order to identify all codes relevant to each condition.

Definitions of categories

**Head injuries**: Used as a proxy indicator of traumatic brain injury (TBI) and includes all non-superficial head injuries. This will include many relatively minor injuries and not all people will have long-term disabilities or require rehabilitation. However, all are serious enough to warrant admission.

Codes: S01 – S09, T040 & T060

**Stroke**: All admissions for any cerebrovascular disease, including sub-arachnoid haemorrhages and any other non-traumatic haemorrhage (bleed) or infarction (blockage). The word 'stroke' has been used as an all encompassing term familiar in general use.

The stroke figures don’t add up to the exact numbers of people who have a stroke as a significant number of people die before admission.

Codes: I60 – I69
**Meningitis**: This is infection of the meninges surrounding the brain. Figures presented include bacterial meningitis, viral meningitis and meningitis of uncertain type. Although viral meningitis is usually relatively mild, it can still cause long-term problems in many cases.

**Codes:**
- Bacterial meningitis: G00 G01 A390 A392 A393 A394 A398 A399 A170 A171 A321
- Viral meningitis: A87 B010 B003 B021 B051 B261 G020
- Other/uncertain meningitis: G021 G028 G03 B375 B451

**Brain tumour**: These include all malignant, benign and uncertain brain tumours. Even benign tumours can cause brain injuries so all are relevant.

**Codes:**
- Malignant tumours: C700 C709 C710 - C719 C751 C753 C793
- Uncertain tumours: D420 D429 D430 D431 D432 D439 D443 D445
- Benign tumours: D320 D329 D330 D331 D332 D339 D352 D354

**Encephalitis**: This is inflammation of the brain caused by infection or through the immune system attacking the brain in error (auto-immune encephalitis). There are many forms of encephalitis, some of which are extremely rare, so as many types as possible have been catalogued under this label.

**Codes:** G04 G05 A811 A83 – A86 B004 B011 B020 B050 B941 B262 F071

**Hydrocephalus**: This is a build-up of cerebrospinal fluid inside the skull, which can increase intracranial pressure and cause injury to the brain. There are several sub-types and the condition can affect all age groups.

**Codes:** G91 G940 G941 G942

**Cerebral abscess**: A pus-filled swelling in the brain caused by an infection. This is a rare but extremely serious condition.

**Code:** G060

**Anoxic brain injury**: The incidences for this code are quite low and may greatly underestimate the actual numbers of hypoxic/anoxic brain injuries. That is because many people who sustain heart failure of different kinds will also have anoxic brain injury as a result but their heart condition will be the primary diagnosis.

**Code:** G931
Carbon monoxide (CO) poisoning: Many people do not realise that CO poisoning causes brain injury. It will not lead to lifelong disabilities in mild cases, but admission to hospital suggests more serious cases leading to possible neurological problems.

Code: T58X

Other disorders: These include toxic encephalopathy, cerebral cysts, unspecified encephalopathy, compression of the brain, cerebral oedema and other specified or unspecified disorders. These conditions are relatively rare so have been combined in one category.

Codes: G92X G930 G934 G935 G936 G938 G939

Sequelae of head injuries: This refers to an effect or condition resulting from a previous head injury. Admissions for this category are low and are not included in English regional figures (this makes no significant difference to the regional totals).

Codes: T901, T902, T903, T904, T905, T908, T909, F072

Regional variations

The codes listed above have been used for England, Wales and Northern Ireland nationally and regionally. Some re-categorisation has been necessary for the age groups and regional figures in order to eliminate numbers lower than five (see Notes, codes and categories pages of the spreadsheets for further information).

ICD-10 codes for sequelae of head injury T900, T901, T902, T903, T904, T905, T908, T909, F072 have been included in the head injury admissions for Northern Ireland. The admissions for these codes are very low so make negligible difference.

Regional figures for England are for residents of Primary Care Trusts (PCTs) up to their dissolution in 2012-13 and Clinical Commissioning Groups (CCGs) in 2013-14. This is decided by post code of residence, so does not record where they were treated. Regional figures for Northern Ireland, Scotland and Wales are also for residents of Local Commissioning Groups (LCGs), Health Boards (HBs) and Local Health Boards (LHBs) respectively.

National and regional figures for Wales have been obtained from freely available data on the NHS Wales Informatics Service website at www.infoandstats.wales.nhs.uk/page.cfm?orgid=869&pid=41010. Total finished admission episode counts are available here but figures for males, females and age groups are published as finished consultant episodes (FCEs). Therefore, finished admission episode counts for males, females and age groups have been estimated based on ratio of FCEs to total FCEs.
Finished admission episodes for Scotland have only been available for head injuries and stroke. Other ABI conditions are grouped with unrelated diagnoses on the ISD Scotland datasets and so are currently unavailable.

The Scotland figures have been accessed from the freely available diagnosis tables on the Information Services Division (ISD) Scotland website at www.isdscotland.org/Health-Topics/Hospital-Care/Diagnoses/. There, superficial head injuries are grouped together with other head injuries so the figures used for this study correct for this by subtracting the average percentage of superficial injuries in the rest of the UK (approx. 17%).

Freely available figures for Scotland are currently only available from the year 2005-06.

Years of study

The annual periods referred to are financial years. For example, if referring to the year 2011-12 the actual period covered is April 1 2011- March 31 2012.

Incidence rates and admission counts

In order to compare regions it is necessary to refer to incidence rates per 100,000. This is because regions vary widely in population so direct comparison of admission numbers isn’t meaningful. The incidence rates cited refer to admissions per 100,000 of the specific population referred to.

All populations for every nation, Primary Care Trust (PCT) (up to their final year of operation in 2012-13), Clinical Commissioning Group (CCG) (2013-14), Health Board (HB) and Local Commissioning Group (LCG) have been obtained for every year covered by this study in order to provide exact incidence rates. National population statistics for England, Northern Ireland, Scotland and Wales have been obtained from the Office for National Statistics (ONS) website at www.ons.gov.uk. PCT and CCG populations have also been obtained from the ONS website. LCG populations have also been obtained from the Northern Ireland Statistics and Research Agency (NISRA) website at www.nisra.gov.uk. Scottish HB incidence rates are based on those published in the Information Services Division (ISD) Scotland diagnosis tables at www.isdscotland.org/Health-Topics/Hospital-Care/Diagnoses/.

Local Health Board populations in Wales have been obtained from the Stats Wales website at https://statswales.wales.gov.uk/Catalogue/Population-and-Migration/Population/Estimates/Local-Authority/PopulationEstimates-by-LocalAuthority-Age.
Age groups

The national data has been broken down into age groups in order to identify those with high incidence of brain injury. The age groups available for each nation vary according to the source. In all cases the age groups have been matched to standardised ranges whose populations are available from the Office for National Statistics. This allows incidence rates per 100,000 of the population to be calculated for each age group.

The ranges for each nation are as follows:

England: 0-4, 5-9, 10-14, 15-19, 20-24, 25-29, 30-34, 35-39, 40-44, 45-49, 50-54, 55-59, 60-64, 65-69, 70-74, 75-79, 80-84, 85+. These five-year ranges are referred to as quinary age groups.

Scotland and Northern Ireland: 0-14, 15-24, 25-34, 45-54, 55-64, 65-74, 75-84, 85+

Wales: 0-14, 15-59, 60-74, 75+

Regional data has not been broken down into age groups.

Patient counts

Finished admission episodes (FAEs) have been used because they are available for all four UK nations and allow comparisons between them. However, the figures slightly overestimate patient numbers because some people are readmitted for the same condition.

It is possible to ‘clean up’ the data by removing subsequent admission episodes for the same individual and the Public Health England Knowledge and Intelligence Teams are able to produce these data. Examples have been obtained for several years and the following figures show the percentage of FAEs for each condition which represents total patients:

- Head injury: 92%
- Stroke: 84%
- Malignant tumours: 45%
- Uncertain tumours: 82%
- Benign tumours: 74%
- All tumours: 53%
- Bacterial meningitis: 75%
- Viral meningitis: 93%
- Other meningitis: 80%
- All meningitis: 83%
- Encephalitis: 75%
- Hydrocephalus: 75%
- Other disorders: 84%
- ABI total: 85%
Number of patients represented by the tumour admissions may be lower still than 53% of admissions. The numbers here are significantly higher than those reported from cancer registry data (which site number of individuals newly diagnosed with cancer). Cancer Research UK cite approximately 9,500 annual cases based on the cancer registry data, whereas this study shows over 17,000 patients in 2013-14. There may be recurring admissions for the same patients included in this, although we do not currently have a definitive explanation for the discrepancy.

Limitations

Admissions to hospital by ICD-10 code do not give information about the severity of the injuries, disability or need for rehabilitation. In fact, many of the admissions will not result in a brain injury.

Many people who do sustain a brain injury will not be included in these figures. This includes those whose injury is classified in a different diagnostic position to primary and those whose brain injury is not diagnosed at all.

Although Headway has tried to provide a comprehensive picture of brain injury, there are still some causes of brain injury that have not been included. For example, heart conditions are a cause of anoxic brain injuries but we do not know how many. We could not include heart conditions in this study because it would artificially inflate the numbers dramatically.

There are also many types of poisoning that can cause brain injury which could not be included, as well as diabetes and forms of electrolyte imbalance (in which the brain cells can become flooded).

References


NHS Health and Social Care Information Centre, 2014.

NHS Scotland Information Services Division, 2014.

NHS Wales Informatics Services, 2014.


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**Further information**

For further information and support about any aspects of the statistics please contact Richard Morris, Publications and Research Manager, at publications@headway.org.uk.