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What's in a number? Problems with counting traumatic brain injuries

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Traumatic brain injury (TBI) is a leading cause of morbidity and mortality worldwide.[1] In survivors, disability may persist for years after the initial injury. Even mild TBI can result in cognitive deficits, somatic symptoms (eg, headaches), mental health problems (eg, depression) and an increased risk of dementia.[2 3] Accurate estimates of the incidence and prevalence of TBI are needed to inform polices on prevention, resource allocation and to meet the needs of those who have sustained a TBI. A recent Lancet Neurology Commission recommended that defining and recording accurate measurements of incidence, mortality and rates of access hospital care in patients with TBI is essential.[1]

A recent analysis of the effect of the Scottish Intercollegiate Guidelines Network head injury guideline, National Institute for Health and Care Excellence (NICE) Guideline 176 (Head injury: assessment and early management), a National Institute for Health Research (NIHR) evidence summary, and numerous peer-reviewed articles and web pages all cite an oft-used statistic that '1.4 million people attend emergency departments in England and Wales with a recent head injury each year'.[4–6] This number has been reported in the medical literature for more than a quarter of a century and forms the basis of our understanding of the public health burden from TBI.

Numerous peer-reviewed articles cite the oft-used statistic that 1.4 million people attend emergency departments in England and Wales each year. The original source of this statistic is elusive.

The source of this statistic for England and Wales is elusive. There is no citation of its origin in the NICE guideline, a common source for contemporary use. An early use is in a 1996 case series of patients with head injury on warfarin.[7] This article references a 1976 Department for Health and Social Security report on head injuries which is only available on paper at the National Archives.[8] Although this report describes hospital admissions for head injury, it does not include data on ED attendance numbers or rates.

The origin of the statistic seems to come from a report of a postal survey from 1994.[9] The authors derive the 1.4 million figure based on an ED attendance rate for head injury of 11%, extrapolated (presumably but not explicitly) from the 1994 total ED attendance numbers. However, the 11% head injury attendance rate is based on the 1974 data from Scotland, a small part of England (Cleveland) and no part of Wales.[10]

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Because the data that inform this statistic are nearly half a century old, based on data from a single devolved nation, and subject to an extrapolation a quarter of a century ago, they are wholly unreliable. Although without contemporary information it is not possible to know whether it is too high, too low or accurate, over the last 50 years the demographic composition of the UK has changed considerably. The population has risen by 20% to 67 million. The proportion of people aged more than 65 has grown. There have been significant changes in the mechanisms of TBI with falls overtaking road traffic collisions as the most common cause, largely secondary to the higher proportion of older adults. Consequently, it seems likely that the statistic is inaccurate.

Why should this number matter? Contemporary and accurate epidemiological statistics are critical for assessing healthcare systems, trends in disease and the effects of therapies. Changes in demographics and emerging therapies for TBI underline the importance in having an updated accurate statistic. However, getting to the true number is not easy.

Problems with case definition and selection bias mean that most epidemiological studies capture only a proportion of head injury or TBI cases, consequently underestimating its incidence and prevalence.[1] Part of the challenge in counting TBI is due to the variety of measures used. Many patients present to hospital after a head injury. However, this is distinct from a brain injury because it is possible to sustain a head injury without a brain injury.

Epidemiological studies report all these, that is, ED attendance rate, hospital admission rate, hospital discharge rate, head injury rate and brain injury rate. Between 1974 and 2018, six studies of the epidemiology of head or traumatic brain injuries in the UK were published.[3] Those studies provide at best patchy coverage of the true picture of head and traumatic brain injury. Most report hospital admission rates. It is estimated that as much of 90% of TBI is mild, and while most patients with mild TBI will not be admitted, in some studies up to 50% of patients have persisting impairment 12 months

after injury.[11] Therefore, current estimates exclude most patients with TBI, and fail to inform both ED utilisation and longer term needs of those with persistent post-concussion symptoms.

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Linked administrative datasets such as the Emergency Care Data Set (ECDS) and Admitted Patient Care Hospital Episode Statistics are a possible solution for accurate contemporaneous epidemiological metrics. A current and ongoing study of 2019 NHS Digital data is designed to identify and discriminate between population and ED attendance incidences of head injury, TBI, intracranial haemorrhage, neurosurgical procedure and death within 28 days of head injury. This study uses ECDS SNOMED-CT codes for head injury and trauma chief complaints and diagnoses, linked with corresponding relevant admission ICD-10 and OPCS-4 codes and with Office for National Statistics mortality data. It will generate definitive epidemiological statistics for 2019, although in time it will, just as the 1.4 million statistic has, become obsolete. Routinely collected administrative datasets have the added benefit that they represent continuously collected rather than cross-sectional data, which means that updated statistics can be relatively easily generated. Regardless of the method, a better understanding of the occurrence of head and traumatic brain injuries is needed in order to facilitate improved care and distribution of resources for those who have been affected by TBI.

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