The Scottish Burden of Disease Study, 2016

Cerebrovascular disease technical overview
Background

The Scottish Burden of Disease (SBoD) study team have published comprehensive estimates of the burden of disease and injury in Scotland for 2016 [1]. The purpose of this technical overview is to provide background information on the data and methodology used, noting any caveats associated with estimating the burden of cerebrovascular disease in SBoD.

Burden of disease studies aim to estimate the difference between ideal and actual health in a country or region at a specific point in time. Individuals can suffer non-fatal health loss due to suffering disability attributable to a disease or injury, or suffer fatal health loss which is early death due to a disease or injury. To quantify the total burden, non-fatal and fatal health loss are combined to produce a single metric called the Disability-Adjusted Life Year (DALY).

In SBoD 2016, all data are presented as three year averages for period 2014-2016. A three year period is used to smooth out most of the effect if the mortality or morbidity of a single year happens to be unusual. Further information about the SBoD study, including a more thorough explanation of the methodology used, overview reports, detailed results and other specific disease briefings, can be found on the website of the Scottish Public Health Observatory (ScotPHO) [1].

Estimated burden due to cerebrovascular disease

Cerebrovascular disease was the 5th most common cause of disease burden in Scotland in 2016, resulting in a total of approximately 56,269 DALYs. Of this total burden, 69% was due to the fatal burden of cerebrovascular disease, with 31% being attributed to the non-fatal burden.

Figure 1 Percentage of total DALYs by gender and age-group for cerebrovascular disease
Women contributed a slightly higher proportion of the burden (54%) than men (46%). Overall, 74% of the total cerebrovascular disease burden was contributed by individuals aged 65 years and over, as outlined in Figure 1. Note that the burden we are describing above is the absolute burden and has not been adjusted for the age/gender case-mix.

The age standardised DALY rates for cerebrovascular disease, by deprivation¹ decile, are shown in Figure 2. The DALY burden increased with increasing levels of deprivation: individuals in the most deprived decile experienced a burden that was more than double that than individuals in the least deprived decile.

Figure 2 DALYs (rates per 100,000²) of total cerebrovascular disease burden by deprivation decile

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¹ We used the Scottish Index of Multiple Deprivation (SIMD 2016) to analyse patterns of inequality in the burden of disease across Scotland. SIMD2016 is categorised into deciles 1 (most deprived) to 10 (least deprived). SIMD2016 calculates deprived areas, not deprived individuals.

² Where the data were age-standardised, this was done directly using the 2013 European Standard Population to account for differences in age structure between SIMD deciles.
How did we produce these estimates?

DALYs attributed to a disease, or injury, are calculated by combining estimates from two individual metrics: Years of Life Lost (YLL) due to premature mortality and Years Lived with Disability (YLD).

Years of life lost (YLL) due to cerebrovascular disease

YLL measures the years of life lost due to premature deaths i.e. the fatal component of burden of disease. YLLs are calculated by subtracting the age at each cerebrovascular disease death from the expected remaining life expectancy for a person at that age.

Estimating the number of deaths

For the period 2014-2016, we estimated an average of 4,200 deaths per year caused by cerebrovascular disease. These deaths were identified from the underlying cause of death on the National Records of Scotland (NRS) register of deaths [2]. To classify deaths the GBD 2015 cause list was used, which has been created using the International Statistical Classification of Diseases and Related Health Problems (ICD-10) [3, 4]. The NRS register of deaths has a Community Health Index (CHI) number attached to each death, which allows for demographic data such as gender, geographical area of residence and age at death to be established for each individual.

Included in the total cerebrovascular disease mortality count are deaths that have come from what are termed ill-defined causes of death in burden of disease studies. These ill-defined deaths are causes of death that have been coded with ICD-10 codes in vital registers but for the purposes of burden of disease studies, are not regarded as sufficiently specific causes of death. In SBoD, these ill-defined deaths are redistributed amongst specific causes of death across the burden of disease cause list based on the secondary causes of death recorded on the death certificate. For a small number of cases, where there was no additional information relating to secondary causes of death, the individuals clinical history was evaluated to inform the target cause for redistribution. For cerebrovascular disease, approximately 6% of the mortality count comes from these ill-defined deaths. For this reason, the number of deaths due to cerebrovascular disease which have been reported are different from that of officially reported sources. Further explanation of this method is available in the SBoD technical paper [1]. Further explanation of this method is available in the Invited chapter of The Registrar General’s Annual Review of Demographic Trends [5].
Life expectancy and YLL

Each single death contributes to the total YLL through calculating the difference between the age at death and the life expectancy at that age. Life expectancy was defined using the 2014-2016 gender-specific National Life Tables for Scotland [6]. There were approximately 38,700 YLL due to cerebrovascular disease in Scotland in 2016. Dividing the total YLL for cerebrovascular disease by the total mortality count indicates that, on average, individuals who die due to cerebrovascular disease die approximately 9 years earlier than would otherwise be expected on the basis of the life expectancy of the general population.

Years lived with disability (YLD) due to cerebrovascular disease

Years lived with disability (YLD) are estimated using:

- disease and injury prevalence estimates
- levels of severity
- disability weights

Our sources of information for these three components are as follows:

Estimating the number of individuals suffering disability

To estimate prevalent cases of cerebrovascular disease and acute events in 2016, the Scottish Morbidity Record 01 (SMR01) was used [7]. This dataset contains structured data in the form ICD-10 codes relating to diagnoses made on discharge from general and acute hospitals during inpatient episodes and day cases. There are up to six individual ICD-10 codes that can be recorded, where the primary diagnosis relates to the main reason for the hospital episode of care, and the other secondary diagnoses refer to co-morbidities that may affect care during that hospital episode of care.

The SMR01 dataset has a CHI number attached to the hospital episode of care, which allows for the identification of records for an individual. This CHI number has been linked to records from the NRS register of deaths, to exclude individuals that have died from prevalence estimates that relate to a period following their date of death [2]. The number of individuals that had a diagnosis of cerebrovascular disease between 1 January 1996 and 31 December 2016 was used to estimate the number of prevalent cases. This period was used because we set 20 years as the standard follow-up period for diseases with life-long consequences. To identify the number of acute events in 2015, the number of individuals that had a primary diagnosis of cerebrovascular disease between 1 January and 31 December 2016 was used. If individuals had multiple primary diagnoses in a given year, then assuming that their consultations were more than 28 days apart, additional cases were recorded.
Using this method of identifying prevalent cases of cerebrovascular disease, we estimated there were approximately 97,000 individuals in the Scottish population living with prevalent cerebrovascular disease in 2016. We also estimated approximately 14,000 acute events of cerebrovascular disease in Scotland.

**Severity distribution and disability weights**

The average duration of an acute event, the levels of severity and disability due to cerebrovascular disease in Scotland were based on the specifications of the GBD 2016 study [8]. This allowed acute events and prevalent cases to be disaggregated by levels of severity and the associated disability at each level of severity. The disability weights were developed by the GBD study through surveys of the general public and take into account the consequences of each disease and injury [9]. The severity distribution and disability weights for cerebrovascular disease are outlined in Table 1 and Table 2.

Once the severity of cerebrovascular disease and associated disability were taken into account, individuals were estimated to be suffering approximately 17,500 YLDs in 2016 due to living with cerebrovascular disease.

**Table 1 Description of severity levels for cerebrovascular diseases with corresponding disability weight for both acute events and chronic cases**

<table>
<thead>
<tr>
<th>Severity level</th>
<th>Description</th>
<th>Disability weight</th>
</tr>
</thead>
<tbody>
<tr>
<td>Mild</td>
<td>Has some difficulty in moving around and some weakness in one hand, but is able to walk without help.</td>
<td>0.019</td>
</tr>
<tr>
<td>Moderate</td>
<td>Has some difficulty in moving around, and in using the hands for lifting and holding things, dressing and grooming.</td>
<td>0.070</td>
</tr>
<tr>
<td>Moderate plus cognition problems</td>
<td>Has some difficulty in moving around, in using the hands for lifting and holding things, dressing and grooming, and in speaking. The person is often forgetful and confused.</td>
<td>0.316</td>
</tr>
<tr>
<td>Severe</td>
<td>Is confined to bed or a wheelchair, has difficulty speaking and depends on others for feeding, toileting and dressing.</td>
<td>0.552</td>
</tr>
<tr>
<td>Severe plus cognition problems</td>
<td>Is confined to bed or a wheelchair, depends on others for feeding, toileting and dressing, and has difficulty speaking, thinking clearly and remembering things.</td>
<td>0.588</td>
</tr>
</tbody>
</table>
### Table 2 Severity distribution for acute events and chronic cases of cerebrovascular disease

<table>
<thead>
<tr>
<th>Severity level</th>
<th>Acute events</th>
<th>Chronic cases</th>
</tr>
</thead>
<tbody>
<tr>
<td>Asymptomatic</td>
<td>0%</td>
<td>19%</td>
</tr>
<tr>
<td>Mild</td>
<td>34%</td>
<td>25%</td>
</tr>
<tr>
<td>Moderate</td>
<td>15%</td>
<td>15%</td>
</tr>
<tr>
<td>Moderate plus cognition problems</td>
<td>18%</td>
<td>20%</td>
</tr>
<tr>
<td>Severe</td>
<td>17%</td>
<td>10%</td>
</tr>
<tr>
<td>Severe plus cognition problems</td>
<td>16%</td>
<td>12%</td>
</tr>
</tbody>
</table>

### Data quality

In order to provide a measure of the degree of accuracy and relevance of the estimated disease DALYs to users, a measure of data quality has been developed for the SBoD study. This measure assigns a RAG (Red; Amber; Green) status to each disease or injury indicative of the accuracy and relevance of the estimates. Interpretation of the RAG status can be defined as follows:

**Highly accurate and relevant**

Estimates have been derived using relevant and robust data sources with only a small degree of adjustments performed to the input data.

**Moderately accurate and relevant**

Estimates have been derived using reasonably relevant and robust data sources with only a moderate degree of adjustments performed to the input data.

**Uncertainties over accuracy and relevance**

Estimates have been derived using less comprehensive or relevant data sources with a high degree of adjustments performed to the input data.

The data quality has been assessed using three main criteria:

- Relevance and accuracy of the data source used to measuring the population of interest
- Likelihood that the implemented disease model captured the overall burden of disease or injury
- The relative contribution of ill-defined deaths to YLL, and YLL to DALY.

These criteria are subjectively assessed and each criterion is scored on a scale of 1 to 5. Further details on these data quality measures are available on the ScotPHO website [1].

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3 How precise, unbiased or certain the estimate is.
4 Do we measure the thing we want to measure?
Based on these criteria, the estimates of burden of cerebrovascular disease in Scotland are highly accurate and relevant.

Our study estimated a cerebrovascular disease prevalence of 2.1% in Scotland in 2016. In comparison, the Global Burden of Disease study (GBD) 2016 estimated a cerebrovascular disease prevalence of 2.1% [10]. Our estimates are not directly comparable to these as GBD did not include any estimate of Transient Ischaemic Attack (TIA) cases [11]. Although the identification of TIAs using health records are challenging, in our study, we have opted to include disability in individuals that experienced a TIA because estimates of cerebrovascular disease mortality include deaths due to TIA, or deaths coded using the wider range of ICD-10 codes relating to cerebrovascular disease.

These health states would not be captured under any other cardiovascular conditions, so to encapsulate the entire burden of cerebrovascular disease, we have chosen to treat the definitions consistently across both non-fatal and fatal domains.

An estimate derived from the 2015/16 Quality and Outcomes Framework (QOF) in Scotland indicated a prevalence of 2.3% [12], whilst results from the Scottish Health Survey 2016 (SHES) estimated a prevalence of 2.9% [13]. Our estimate of 2.1% is, therefore, in line with other comparable Scottish-based findings; however there is the likelihood that TIAs will be under-recorded on secondary care records [14].

What next to improve estimates for cerebrovascular disease?

Future work on the SBOD study will attempt to refine the estimates of prevalence. This work will include reviewing the coding and recording of cerebrovascular disease in alternative national datasets. Further to this, work will be carried out to attempt to derive estimates of severity levels that are dependent on age and that are specific to the Scottish population.

These improvements are partly dependent on exploring other data sources and reviewing evidence from high quality research that it is relevant to Scotland. Please contact the SBoD project team (nhs.healthscotland-sbod-team@nhs.net) for enquiries and suggestions on how to improve our estimates.
References


