Scottish Burden of Disease study

Supplementary appendix for sub-national estimates

Burden of disease methodology

The Scottish Burden of Disease (SBoD) study [1] standardises estimates of ill-health and early death in a composite measure called Disability-Adjusted Life Years (DALYs), also referred to as health loss. It does this by framing ill-health and early death in terms of health loss as a function of time. Estimates of the frequency of ill-health, such as prevalence, are transformed into Years Lived with Disability (YLD), using disability weights from the Global Burden of Disease (GBD) study [2]. Mortality estimates are converted into Years of Life Lost to premature mortality (YLL) by estimating the excess life expectancy lost due to death at a given age using an aspirational life table.

An applied example of how YLD, YLL and DALYs are calculated is given in the infographic below.

Three people experienced health loss in different ways...

<table>
<thead>
<tr>
<th>Description</th>
<th>YLD</th>
<th>YLL</th>
<th>Years of Life Lost</th>
</tr>
</thead>
<tbody>
<tr>
<td>A 50-year old man suffered from severe anxiety. He feels constantly worried and anxious, and often thinks of suicide. This amounted to 0.523 lost years of healthy life.</td>
<td>0.523</td>
<td></td>
<td>30.30</td>
</tr>
<tr>
<td>A 45-year old woman suffered from severe neck pain. She had difficulty turning her head or lifting things, and problems with sleeping. This amounted to 0.229 lost years of healthy life.</td>
<td>0.229</td>
<td></td>
<td></td>
</tr>
<tr>
<td>A 60-year old woman died from a stroke. Having lived to this age her aspirational life expectancy was 90.3 years, so there were 30.30 lost years due to premature mortality.</td>
<td></td>
<td>30.30</td>
<td></td>
</tr>
</tbody>
</table>

Disability-adjusted Life Years (DALYS) = YLD + YLL

This hypothetical example resulted in approximately 31 DALYS, representing the combined direct impact on ill-health and premature mortality.
Guide to using SBOD sub national area estimates

- **DALYs** measure total health loss from the debilitating effects of ill-health and early death.

- **YLD** (or ill-health) depends on the frequency of ill-health and the level of disability that is experienced. This means that highly prevalent conditions do not necessarily result in high levels of YLD if the disability weight is low. Long-term causes which are, on average, successfully treated or managed have relatively low disability weights.

- **YLL** (or early death) depends on the frequency of mortality and the age at which the death occurs. YLL accrues faster for deaths at younger ages compared to older ages. It may be possible for an area to have a higher death rate than another area, but have a lower YLL rate if the deaths were at older ages.

- YLD estimates for sub-national areas, between 2014 and 2019, are based on expected results only and have been modelled using the national age, sex and deprivation morbidity rates generated as part of the SBoD study.

- YLL and mortality estimates are based on the annual death registrations for each sub-national area between 2014 and 2019. Around 1 in 10 death registrations were proportionally distributed to multiple cause of disease and injury.

- The lower the granularity, the more uncertain results can become, especially for causes where the prevalence or mortality count is low. Where possible, it is essential to cross-check any comparisons with the underlying prevalence and/or mortality estimates.

- Both the absolute number of years lost (YLD, YLL and DALYs) and age-standardised rate per 100,000 population are reported.

- Direct age-standardisation of rates is essential for cross-area comparisons. Care must be taken when interpreting comparisons that are based on small numbers as it may lead to inappropriate conclusions, especially where differences are largely exaggerated.
Geographical areas

The SBoD study has produced estimates at national level and at the following sub-national levels: regions (3), NHS boards (14) and local authorities (32). Populations for each of these areas were sourced from National Records of Scotland (NRS), based on mid-year population estimates [1]. Regions are based on NHS Scotland Workforce regions where: **East Region** – NHS Borders, NHS Fife and NHS Lothian; **North Region** – NHS Highland, NHS Grampian, NHS Orkney, NHS Shetland, NHS Western Isles and NHS Tayside; **West Region** – NHS Ayrshire and Arran, NHS Dumfries and Galloway, NHS Forth Valley, NHS Greater Glasgow and Clyde and NHS Lanarkshire [3].

Cause list

The SBoD study burden of disease classification is divided into three hierarchical levels. The first level comprises of: communicable, maternal, neonatal, and nutritional diseases; non-communicable diseases; and injuries. Within these three categories, individual diseases are further grouped into broad disease groups e.g. cancers, cardiovascular diseases and musculoskeletal disorders. The individual diseases or injuries e.g. ischaemic heart disease, stroke, and atrial fibrillation, are grouped within each broad disease group. Overall, the SBoD study reports on over 100 individual diseases and injuries, which is based on an abridged version from the Global Burden of Disease 2019 study [5]. For the sub national area estimates, a further abridged list of 70 individual diseases and injuries has been utilised.

Estimates of mortality

Data

Death registrations in Scotland were sourced from the NRS register of deaths [4] for the period 01 January 2014 to 31 December 2019. Death records were allocated to each geographical area based on an individual’s postcode of residence at time of death. Therefore, sub-national area estimates of early death (YLL) reflect the most recently recorded local area residency of an individual when they died.

A measure of life expectancy is required in order to calculate the YLL at any given age of death. In the most recent update of the SBoD study, we have defined life expectancy based on aspirational values reflecting the situation that health loss is measured relative to the highest standard which has been achieved globally. This is a change from SBoD2016 where YLL estimates were based on sex-specific national life tables for Scotland and which resulted in lower estimates of early death (YLL) and total health loss (DALY). This change was implemented to allow for the full extent of local, national and international inequality to be explored. Using an aspirational life table provides a much higher life expectancy than that from Scottish national life tables and assigns the same life expectancy to men and women. This approach also allows SBoD estimates to be comparable with those of the Global Burden of Disease study.

Allocating deaths to causes

Death registrations were allocated to causes of death based on the International Statistical Classification of Diseases and Related Health Problems 10th revision.
ICD10 codes [6] that were coded on the death registration record. In burden of disease studies, these ICD-10 codes are grouped into cause-specific and ill-defined codes. Cause-specific codes refer to codes that are directly attributed to one of the individual diseases or injuries in our burden of disease classification. Ill-defined death (IDD) codes, also referred to as ‘garbage codes’, are codes that are deemed not to be valid causes of death for the purpose of burden of disease studies, e.g. senility, atherosclerosis and hypertension. The first step in allocating deaths to individual causes is to allocate cause-specific deaths based on the ICD-10 code recorded as the underlying cause of death. The next step in the process was to allocate the IDDs. This is done using a redistribution algorithm, designed to utilise as much information from the death certificate as possible. Further information on this method can be found in the Invited Chapter of the 2017 Registrar General’s Annual Review [7].

Estimates of ill-health

As part of the national SBoD study, we estimate ill-health (YLD) for each individual disease and injury included in the SBoD disease classification, using a range of data sources e.g. primary care, secondary care, national surveys and disease registers.

Data

For the majority of causes of disease or injury in the SBoD study, estimates have been made using data sources which contain a patient Community Health Index (CHI) number which was harnessed to enable the linkage of routine administrative data. The advantage of using datasets which contained CHI numbers was that the CHI enabled us to derive information relating to the patient demographics such as age, gender or socioeconomic status. The presence of a CHI number also allowed us to censor patients from estimates of morbidity when they died, and furthermore, allowed us to search across several datasets to ensure that our estimates of ill-health were as extensive as possible. An example of this was where we linked records from unscheduled care services with hospitalisation episode’s data for a more comprehensive assessment of the burden of injuries.

Where non-routine sources of data were used to define estimates of ill-health e.g. Quality and Outcomes Framework (QOF) register data, national population surveys (e.g. Scottish Health Survey) or surveillance of communicable disease data, it often did not include the full information which was necessary to produce the level of estimates which were required, in terms of demographic breakdown. This meant that the SBOD study team needed to make inferences on how to distribute the total number of cases by demographic (age, gender and socioeconomic status). The process for doing this was to base the underlying distribution of total cases on the most relevant source of data for which a distribution could be obtained. For example, when using the aggregate Scotland total QOF register to define the total number of prevalent cases of asthma, the cases were distributed into specific age-gender-socioeconomic groups on the basis of the distribution that was observed for asthma GP consultations from the Practice Team Information dataset.

Further information on how estimates were obtained for specific conditions can be found in the form of individual Technical Reports on the SBoD archive area of the ScotPHO website [8].
Severity and disability
In burden of disease studies, a measure of disability is required to apportion the level of health loss experienced by a given condition. The disability weights used in the SBOD study were those which were used in the GBD 2016 study [2]. These weights give a level of disability for each cause of disease and injury graded between 0 (no disability) to 1 (death), with higher levels of disability being an indicator of more debilitating causes of disease or injury. The GBD 2016 study defines disability weights at the health state level, rather than that by individual cause. A health state is groupings of disease sequelae that reflect key differences in symptoms and functioning. For each cause, the estimated proportions of how morbidity should be allocated into severities (e.g. mild, moderate and severe disease) is more commonly referred to as a severity distribution. To facilitate calculations of disability weights for each cause, we used the severity distributions published in GBD 2016, with the exception of cirrhosis, epilepsy and all cancer types, where we derived our own using Scottish specific estimates.

Creating sub-national area estimates of ill-health
Whilst we were able to extract, or impute, information relating to an individual’s demographic characteristics (age, gender, socioeconomic status) we were not able to gain inferences into the observed distribution of ill-health into local geographies for each cause. To facilitate estimates of ill-health by sub-national area, we created estimates of ill-health rates by 5-year age-group, gender and Scottish Index of Multiple Deprivation (SIMD) decile [9]. This resulted in 400 stratifications of morbidity rates for each of the 132 causes. These rates were used in conjunction with NRS mid-year population estimates [1] for each sub-national area to estimate the expected prevalence and YLD for each sub-national area. Although sub-national estimates have been published across 70 individual diseases and injuries, they were calculated for each of the 132 diseases or injuries and aggregated to form the abridged cause list to ensure that estimates were made using the lowest granularity of information available.

For our current update of estimates from 2014 to 2019, the burden of ill-health at national level has been modelled based on the estimates of prevalence derived for the 2016 Scottish Burden of Disease estimates. Prevalence and YLD rates at age, sex and deprivation have been applied to 2019 population estimates to generate national estimates for 2019. Estimates for local areas have then been modelled using these national results and local age, sex, deprivation population profiles.

Uncertainty over estimates
SBoD estimates do not currently contain confidence intervals, because confidence intervals only capture the uncertainty around the point-estimate, rather than additional uncertainties, such as uncertainties in severity distributions, disability weights or whether the data which estimates are based upon is representative of the full population. These factors are important, and the provision of confidence intervals would underplay their value.

Estimates of ill-health are based on national prevalence and YLD rates and should be treated as expected values rather than observed. Estimates of mortality and early death are based on observed local data, Death estimates (numbers and rates) have
been suppressed for all local authorities for age-groups under 25 years. The effect of this has been carried through to NHS board and regional death estimates which have also been appropriately suppressed to avoid differencing.

To reflect the uncertainty associated with small numbers and rates, any estimate which is (deaths), or is based on (YLL and DALYs) a death count of less than 5 has been flagged as based on ‘small numbers’ in the data tables available from our local geography data visualisation. Exceptions to this are causes of disease that were not deemed possible causes of death in burden of disease studies (headache disorders, anxiety disorders, depression, osteoarthritis, low back and neck pain, sensory conditions and dental health conditions). Users of the SBoD local sub national area profiles should be aware of the data underlying any estimates, particularly for YLL as it accumulates as a much faster rate than YLD, so data based on small numbers of death can quickly rise to several hundred YLL. Please refer to the ‘Guide to using SBOD local estimates’ on page 2 of this technical report.

In order to provide a measure of the degree of accuracy and relevance of estimates to users, we have developed a measure to indicate the data quality of estimates. This measure assigns a RAG (Red; Amber; Green) status to each cause of disease or injury indicative of the accuracy and relevance of the estimates. Interpretation of the RAG status can be defined on the continuous scale outlined below:

Scores towards the GREEN end of the scale can be assumed to be highly accurate and relevant, as they have been developed using robust sources with up to a small degree of adjustments made to the input data. Moderately accurate and relevant scores sit in the AMBER range. These are deemed to be reasonably relevant and robust data sources with up to moderate degree of adjustments performed on the input data. Those scores towards the RED end of the scale have been derived using less comprehensive or relevant data sources with a high degree of adjustments performed to the input data and should be treated as having a large degree of uncertainty.

The data quality was assessed using the criteria below, on a scale of 1 to 5, with the weighted scores being assessed on a continuous scale:

**Ill-health (YLD and prevalence):**
- Relevance and accuracy of the data source used to measure the population of interest;
- Degree of adjustments performed to the input data;
- Likelihood that the implemented disease model captured the burden of ill-health.

**Mortality (YLL and deaths):**
- Contribution of ill-defined deaths as a total of all deaths.
DALYs:
- Weighted-average of ill-health (YLD) and early death (YLL) scores, where the weights were defined as the proportions of YLD and YLL of DALYs for the given disease or injury, for all ages and both sexes.

Additional information

Further information relating to any of the technical aspects of the processes in the SBoD study, please contact the SBoD study team (phs.sbod@phs.scot).
References


