The Scottish Burden of Disease Study, 2016

Diabetes 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 diabetes 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 to diabetes

Diabetes was the 12th most common cause of disease burden in Scotland in 2016, resulting in approximately 30,800 DALYs. Of this burden, 34% was due to premature mortality attributed to diabetes and 66% was attributed to health loss suffered due to living with diabetes.

Figure 1 Percentage of total DALY by gender and age-group for diabetes

<table>
<thead>
<tr>
<th>Age Group</th>
<th>% of total DALYS for diabetes in Scotland</th>
</tr>
</thead>
<tbody>
<tr>
<td>under 15</td>
<td></td>
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<tr>
<td>15-24</td>
<td></td>
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<tr>
<td>25-44</td>
<td></td>
</tr>
<tr>
<td>45-64</td>
<td></td>
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<tr>
<td>65 and above</td>
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The percentage of the total diabetes DALY was greater for men (55%) than women (45%). Overall, people aged 65 years and over accounted for over half (53%) of the total diabetes burden in Scotland in 2016: men in this age group contributed a slightly higher proportion (27%) to the total burden than women (26%). Men aged 45-64 years accounted for 21% of the total diabetes burden, compared to 15% of women aged 45-64 years. Men aged 25-44 years accounted for 6% of the total diabetes burden, compared to 4% of women aged 25-44 (Figure 1). Note that the burden which we are describing above is the absolute burden and has not been adjusted for the age/gender case-mix.

The burden of diabetes increased with increasing levels of deprivation\(^1\), as outlined in Figure 2. Individuals in the most deprived decile experienced a burden that was 2.3 times greater than individuals in the least deprived decile.

**Figure 2 Diabetes DALY (rates per 100,000\(^2\)) by deprivation decile**

\(^1\) 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 due to diabetes

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 skin and subcutaneous 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 833 deaths per year caused by diabetes. There were approximately 833 deaths caused by diabetes in 2016. 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 2016 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 diabetes mortality count are deaths that have come from what are termed ill-defined cause of deaths in burden of disease studies. These ill-defined deaths are causes of death that have been coded with ICD10 codes in vital registers but for the purposes of burden of disease studies, are not regarded as sufficiently specific causes of death [3]. 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 individual’s clinical history was evaluated to inform the target cause for redistribution. For diabetes, approximately 1% of the mortality count comes from these ill-defined deaths. For this reason, the number of deaths due to diabetes which have been reported are different from that of officially reported sources. 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 10,300 years lost to premature mortality caused by diabetes in Scotland in 2016. Dividing the total YLL for diabetes by the total mortality count for diabetes indicates that, on average, individuals with diabetes die approximately 12 years earlier than one would otherwise be expected on the basis of the life expectancy of the general population.

Years lived with disability due to diabetes

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 were as follows:

**Estimating the prevalence**
To estimate prevalent cases of diabetes in 2016, the Scottish Diabetes survey (2016) was used [7]. The Scottish Diabetes Survey is the most complete routine data source for diabetes in Scotland. Based on data provided by all 14 Scottish health boards, it combines information from primary and secondary care. The survey provides data on the number of people with diabetes, the effects on their health, and the progress being made to improve the delivery and outcomes of care for diabetes. Data for this survey is extracted from the **Scottish Care Information – Diabetes Collaboration (SCI-DC)**, NHS Scotland’s diabetes patient management system, which is used in every health board and holds data on all people with diabetes living in Scotland. The SCI-DC database was rolled out across Scotland from 2000 and the estimated coverage of the total diabetic population is around 99% [8].

Using this method of identifying prevalent cases of diabetes, the 2016 Scottish Diabetes Survey estimated that there were approximately 292,000 individuals in the Scottish population living with diabetes in 2016.
Severity distribution and disability weights

The levels of severity and disability due to diabetes in Scotland were based on the specifications of the GBD 2016 study [9]. This allowed us to disaggregate the prevalent cases into 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, condition and injury [10]. The severity distributions and disability weights for diabetes are outlined in Table 1.

These severity distributions and disability weights were applied to the estimated number of people living with diabetes (n= approx. 292,000), resulting in a total of 20,400 YLD due to diabetes in Scotland in 2016.
Table 1 Description and allocation to severity levels for diabetes with corresponding disability weight

<table>
<thead>
<tr>
<th>Severity level</th>
<th>Description</th>
<th>% of individuals</th>
<th>Disability weight</th>
</tr>
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<tbody>
<tr>
<td>Uncomplicated diabetes mellitus</td>
<td>Has a chronic disease that requires medication every day and causes some worry but minimal interference with daily activities.</td>
<td>65</td>
<td>0.049</td>
</tr>
<tr>
<td>Diabetic neuropathy</td>
<td>Has pain, tingling and numbness in the arms, legs, hands and feet. The person sometimes gets cramps and muscle weakness.</td>
<td>28</td>
<td>0.133</td>
</tr>
<tr>
<td>Diabetic foot due to neuropathy</td>
<td>See ‘Diabetic neuropathy’</td>
<td>2</td>
<td>0.133</td>
</tr>
<tr>
<td>Diabetic neuropathy and amputation without treatment</td>
<td>See ‘Diabetic neuropathy’</td>
<td>1</td>
<td>0.133</td>
</tr>
<tr>
<td>Diabetic neuropathy and amputation with treatment</td>
<td>See ‘Diabetic neuropathy’</td>
<td>1</td>
<td>0.031</td>
</tr>
<tr>
<td>Moderate vision impairment due to diabetes mellitus</td>
<td>Has severe vision loss, which causes difficulty in daily activities, some emotional impact (for example worry), and some difficulty going outside the home without assistance.</td>
<td>less than 1</td>
<td>0.031</td>
</tr>
<tr>
<td>Severe vision impairment due to diabetes mellitus</td>
<td>Is completely blind, which causes great difficulty in some daily activities, worry and anxiety, and great difficulty going outside the home without assistance.</td>
<td>less than 1</td>
<td>0.184</td>
</tr>
<tr>
<td>Blindness due to diabetes mellitus</td>
<td>Is completely blind, which causes great difficulty in some daily activities, worry and anxiety, and great difficulty going outside the home without assistance.</td>
<td>less than 1</td>
<td>0.187</td>
</tr>
</tbody>
</table>
Data quality

In order to provide a measure of the degree of accuracy\(^3\) and relevance\(^4\) 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:

**RAG 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.

**RAG 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.

**RAG 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].

Based on these criteria, the estimates of burden of diabetes in Scotland are **RAG highly accurate and relevant**.

We have used a national diabetes survey based on data from a national diabetes register with near complete population coverage. The Scottish Care Information-Diabetes Collaboration (SCI-DC) database, registers data on all individuals assigned a diagnosis of diabetes by their clinicians for 99.5% of general practices nationally. Diagnostic coding levels are very high for adults because they are required to receive payments under the general practice United Kingdom pay-for-performance program [11]. A validation study among the subset of people with diabetes mentioned on a hospital record in 2007 found that 99% were included in the diabetes register [8].

\(^3\) How precise, unbiased or certain the estimate is.
\(^4\) Do we measure the thing we want to measure?
However, our estimate of diabetes prevalence does not take into account people with type 2 diabetes who have few symptoms and who are not diagnosed as diabetic. Estimates of this undiagnosed diabetic population in Scotland have ranged from 2.5% to 12% in those aged 16 years and over [12, 13]. Applying an undiagnosed population rate of 12% to our current diabetic prevalence, would result in an extra 34,500 prevalent cases. If we were to assume that this undiagnosed population all had uncomplicated diabetes, the additional YLD contributed by this undiagnosed population would increase YLD by approximately 1700 though diabetes would remain as the 12th leading contributor to disease burden in Scotland.

**What next to improve estimates for diabetes?**

Future iterations of the SBOD will work to refine our estimates of prevalence to take into account the estimated undiagnosed diabetic population in Scotland. Further to this, work will be carried out to attempt to derive estimates of severity levels for diabetes using data from the Scottish Care Information – Diabetes Collaboration that are dependent on age and that are specific to the Scottish population.

These improvements are partly dependant 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


