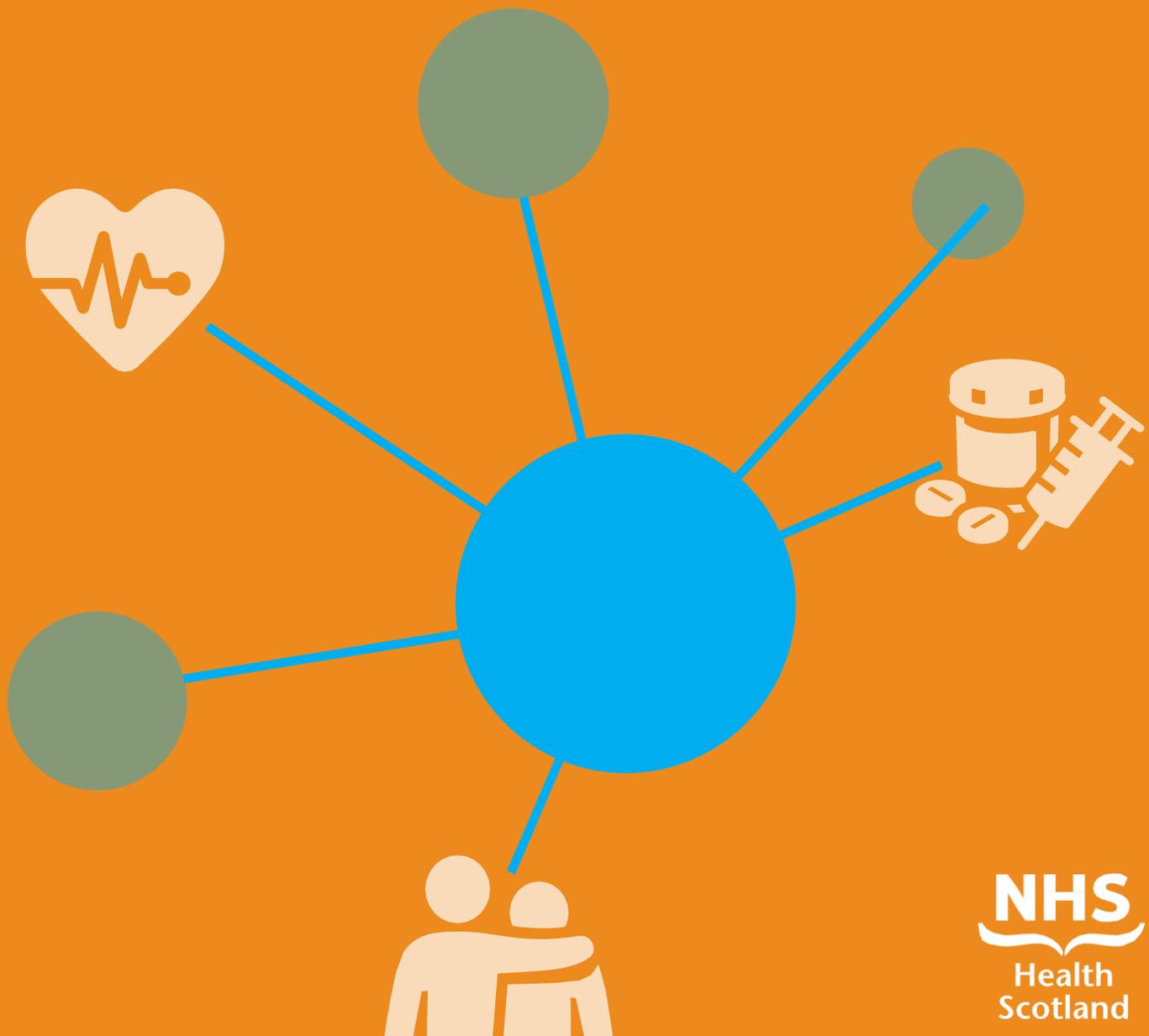


The Scottish Burden of Disease Study, 2016

Chronic liver disease technical overview



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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 cirrhosis and other chronic liver diseases, decompensated (CLD) in SBoD.

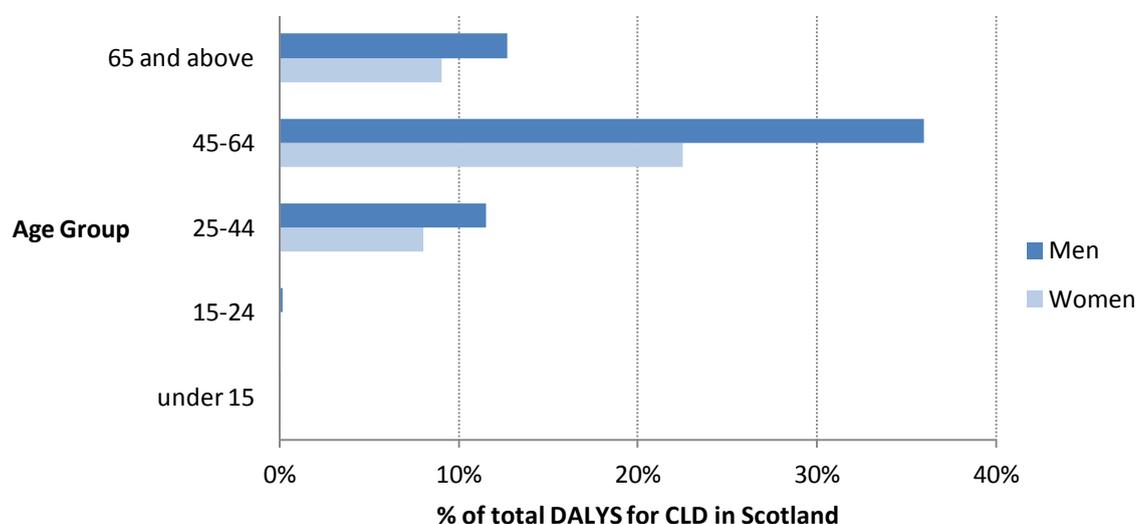
Burden of disease studies aim to estimate the difference between ideal and actual health in a country or region at a specific point in time. Individuals can suffer non-fatal health loss due to suffering disability attributable to a disease, condition or injury, or suffer fatal health loss which is early death due to a disease, condition 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 chronic liver disease

CLD was the 14th most common cause of disease burden in Scotland in 2016, resulting in a total of approximately 27,500 DALYs. Of this total burden, 93% was due to premature mortality attributed to CLD and 7% was attributed to health loss suffered due to living with CLD.

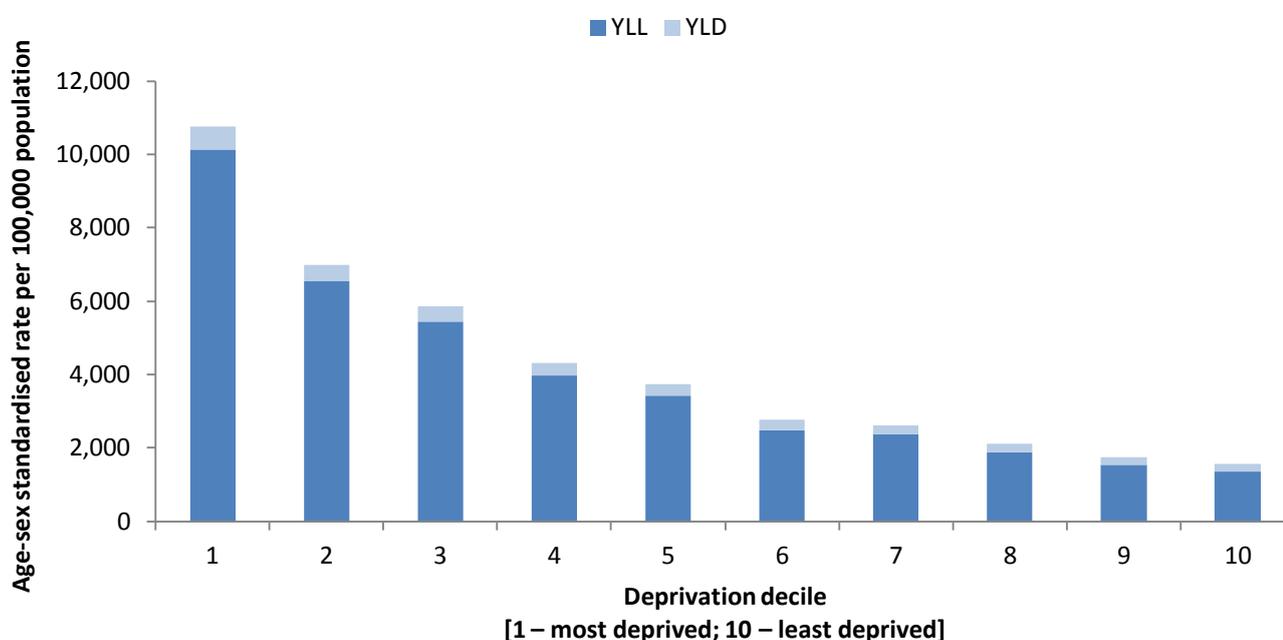
Figure 1 Percentage of total DALYs by gender and age-group for CLD



Men contributed a higher proportion of the burden (60%) than women (40%). Overall, 80% of the total CLD burden was contributed by individuals aged 45 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 CLD, 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 7 times greater than individuals in the least deprived decile.

Figure 2 DALY (rates per 100,000²) of total CLD burden 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, condition 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 chronic liver 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 CLD 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 1,100 deaths per year caused by CLD. There were approximately 1,100 deaths caused by CLD 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 CLD 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 CLD, approximately 1% of the mortality count comes from these ill-defined deaths. For this reason, the number of deaths due to CLD 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 2013 gender-specific National Life Tables for Scotland [6]. There were approximately 25,500 YLL due to CLD in Scotland in 2016. Dividing the total YLL for CLD by the total mortality count indicates that, on average, individuals who die due to CLD die approximately 23 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 chronic liver 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 prevalence

To estimate prevalent cases of CLD in 2016, the Scottish Morbidity Records 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 primary diagnosis of CLD between 1 January 1997 to 31 December 2016 was used to estimate the number of prevalent cases.

Using this method of identifying prevalent cases of CLD, we estimated that there were approximately 33,200 individuals in the Scottish population living with CLD in 2016.

Severity distribution and disability weights

The levels of severity were based on the severity distribution from the The SCottish Alcoholic Liver disease cohort study [8] and the disability due to CLD 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 distribution and disability weights for CLD are outlined in Table 1.

Table 1 Description and allocation to severity levels for CLD with corresponding disability weight

Severity level	Description	% of individuals	Disability weight
Compensated cirrhosis of the liver	No symptoms. Liver can still function	67	0.000
Decompensated cirrhosis of the liver	Has a swollen belly and swollen legs. The person feels weakness, fatigue and loss of appetite.	33	0.178

Once the severity of CLD and associated disability were taken into account, individuals were estimated to be suffering approximately 2,000 YLDs in 2016 due to living with CLD.

Data quality

In order to provide a measure of the degree of accuracy³ and relevance⁴ 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.

³ How precise, unbiased or certain the estimate is.

⁴ Do we measure the thing we want to measure?

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 CLD in Scotland are green,  **highly accurate and relevant.**

We have chosen to use hospital diagnosis records to estimate the number of individuals suffering disability due to (compensated/decompensated) CLD. Due to the progression of CLD, which can result in health loss and poor outcomes, hospital records are likely to be a good resource to estimate prevalence, especially in those patients that have CLD for some time and whose liver is unable to compensate for prior cirrhotic damage [9].

Our study estimated a CLD prevalence of 0.62% in Scotland in 2016. In comparison, the Global Burden of Disease study (GBD) 2016 estimated a higher CLD prevalence of 1.11% [11]. A study carried out across the UK, using records from primary care over a 10-year period, estimated a prevalence of 0.76% for individuals aged 25 and above [12]. The same study also indicated that 38% of CLD was alcohol-related. Given the causal link between CLD and alcohol consumption, combined with the fact there are known issues with excess alcohol use in Scotland [13], we believe that using Scottish health records to describe the burden would be the most relevant approach.

What next to improve estimates for chronic liver disease?

Future work on the SBoD study will include reviewing the coding and recording of CLD in alternative national datasets. The development of the Scottish Primary Care Information Resource (SPIRE) will provide another source to estimate the prevalence of CLD for comparison [13]. 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 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.

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