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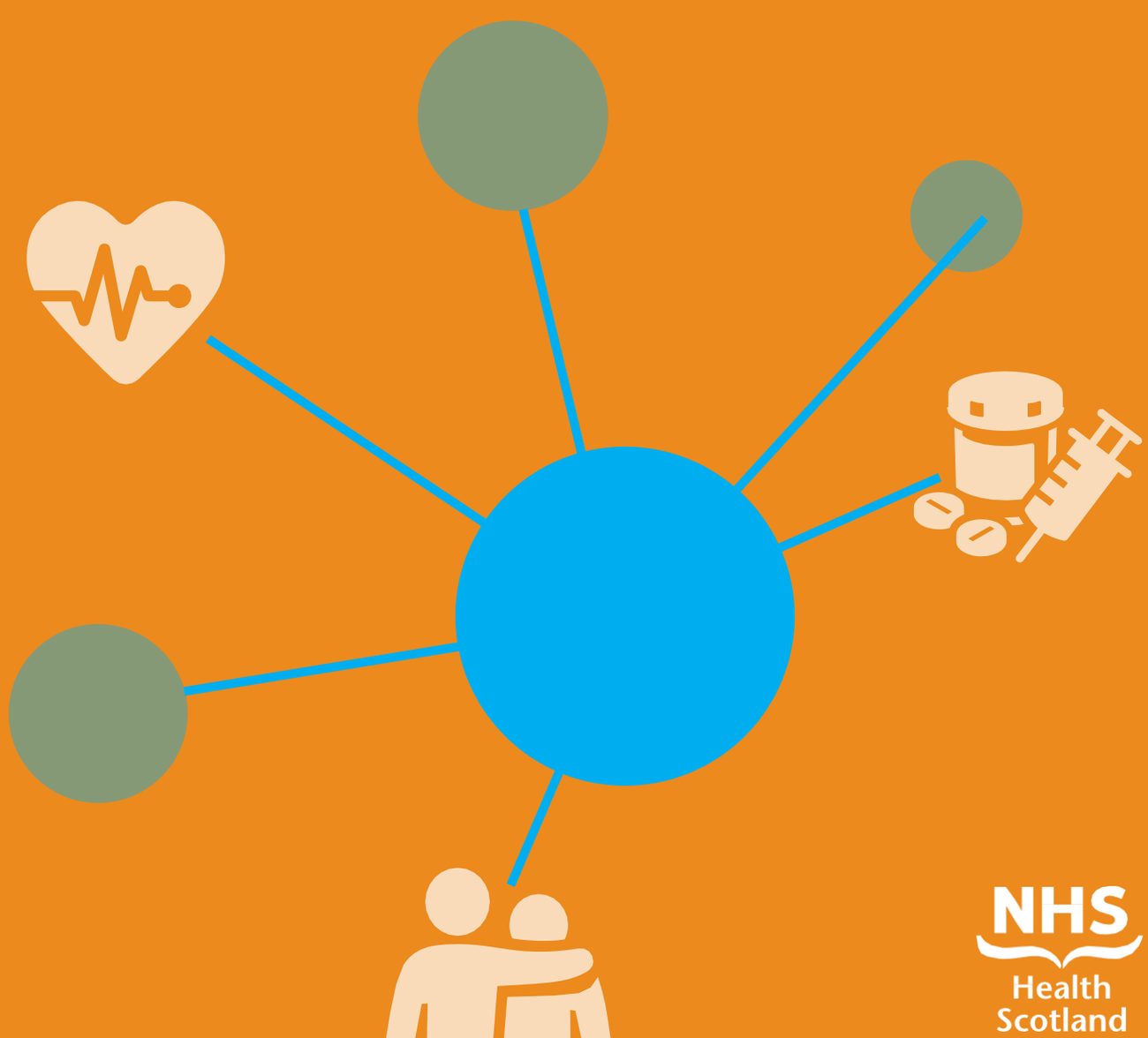
The Scottish Burden of Disease Study, 2016

Chronic obstructive pulmonary 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 chronic obstructive pulmonary disorder (COPD) in SBoD.

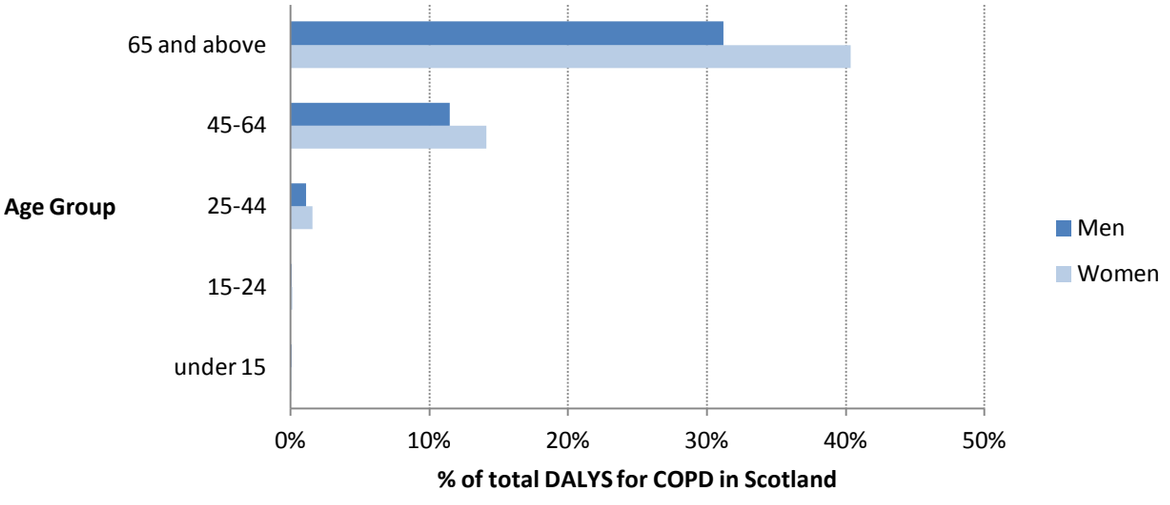
Burden of disease studies aim to estimate the difference between ideal and actual health in a country or region at a specific point in time. Individuals can suffer non-fatal health loss due to suffering disability attributable to a disease or injury, or suffer fatal health loss which is early death due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

COPD was the ninth most common cause of disease burden in Scotland in 2016, resulting in a total of approximately 47,600 DALYs. Of this total burden, 83% was due to premature mortality attributed to COPD and 17% was attributed to the health loss suffered due to living with COPD.

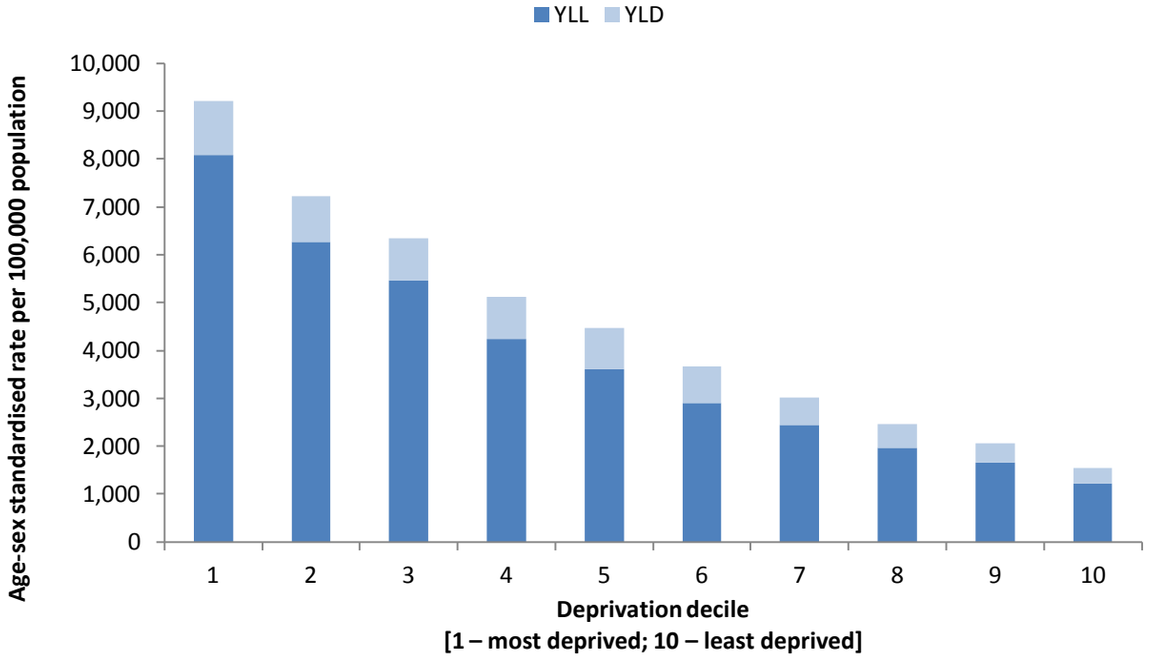
Figure 1 Percentage of total DALYs by gender and age-group for COPD



The percentage of the total COPD DALY was greater for women (56%) than men (44%). Overall, individuals aged 65 years and over accounted for two thirds (66%) of the total COPD burden in Scotland in 2015. Women in this age group contributed a higher proportion (40%) to the total burden than men (14%). Women aged 45-64 years accounted for 18% of the total COPD burden, compared to 11% for men aged 45-64 years. At younger ages, there were no differences between men and women, 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 COPD, by deprivation[1] decile, are shown in Figure 2. Individuals in the most deprived decile experienced a burden that was 6 times greater than individuals in the least deprived decile.

Figure 2 DALYs (rates per 100,000[2]) of total COPD 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, 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 COPD

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 COPD 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 3,600 deaths per year caused by COPD. 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 Global Burden of Disease (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 COPD 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 ICD10 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 COPD, approximately 10% of the mortality count comes from these ill-defined deaths. For this reason, the number of deaths due to COPD 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 39,400 YLL due to COPD in Scotland in 2016. Dividing the total YLL for COPD by the total mortality count indicates that, on average, individuals who die due to COPD, die approximately 11 years younger than would be otherwise expected on the basis of the life expectancy of the general population.

Years Lived with Disability (YLD) due to COPD

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 COPD in 2016, data from the Quality & Outcomes Framework (QOF) was used [7]. The QOF meansures a General Practices achievement against a set of evidence based indicators. Payments are made to each general practice based on the achievements against these indicators. QOF was major part of the new General Medical Services (GMS) contract, which was introduced on 1st April 2004 and decommissioned on the 31st March 2016. QOF contains information on General Practices with a registered population in Scotland. The QOF measures achievement against a range 74 indicators and includes quality indicators for COPD. Prevalence data within the QOF are collected in the form of practice ‘registers’. A QOF register may count patients with one specific disease or condition, or it may include multiple conditions. There may also be other criteria for inclusion on a QOF register, such as age or time of diagnosis.

We used QOF COPD prevalence rates (2.3 per 100) as at 1st April 2016 to estimate our total prevalence count for COPD [8]. The total prevalent estimate was later redistributed to different deprivation decile, age groups and gender based on the proportions we obtained from the Practice Team Information dataset (PTI) [9]. This dataset was collected by ISD Scotland from April 2003 to September 2013. It includes information from a nationally representative 5% sample of Scottish General Practices regarding face-to-face consultations between individuals and a member of the practice team (GPs, nurses and clinical assistants). The presence of a unique patient-identifier on the dataset allows for the grouping of consultations for each individual. The reason for each consultation was coded using Read codes. The number of individuals that had a Read code specific to COPD between 1 April 2003 and 31 September 2013 were used to estimate the age groups and gender proportions. The list of Read codes we used to identify COPD consultations can be found on the ScotPHO website [1]. We used the average number of individuals consulting for COPD per year, for the time period covered by PTI (2003-2013) to estimate the number of prevalent cases in 2014, 2015, and 2016. There is no information about the death of individuals in QOF, so adjustments are made to account for deaths were made using average mortality rates for each age, gender and deprivation decile in Scotland and the excess mortality occurring in COPD cases reported by the NHANES III Follow-up Study [10].

Using this method of identifying prevalent cases of COPD, we estimated that there were approximately 123,800 individuals in the Scottish population living with COPD in 2016

COPD and heart failure

The GBD 2016 study [9] assigns a different disability weight and severity distribution to prevalent cases of COPD and COPD with heart failure and for that reason we estimated prevalence of COPD and COPD with heart failure independently. While we considered QoF [7] to be the best data source for COPD prevalent cases, we used the Scottish Morbidity Record 01 (SMR01) to identify cases of COPD and heart failure. This dataset contains structured data in the form of International Statistical Classification of Disease (ICD-10) [4] codes relating to diagnoses made on discharge from a secondary care setting. There are up to six individual ICD-10 codes that can be recorded, where the primary diagnosis relates to the main reason for the episode of care, and the other secondary diagnoses provide more information, for instance the co-morbidities that may affect the individual during that episode of care. The list of ICD-10 codes that were used to define mortality due to COPD was also used to identify prevalent cases of COPD. Heart failure prevalent cases were identified by looking for ICD-10 code I50 ‘heart failure’ in any of diagnosis fields in SMR01.

The SMR01 dataset has a Community Health Index (CHI) number attached to the episode of care, which allows for the identification of records for an individual. This CHI number has been linked to records from the National Records of Scotland (NRS) register of deaths, to exclude individuals that have died from estimates following their date of death. The number of individuals that had both a diagnosis of COPD and heart failure between 1 January 1996 to 31 December 2016, and these two diagnosis happened in a time span no longer than two years, was used to estimate the number of prevalent cases of COPD with heart failure. We excluded individuals that had also a diagnosis of ischaemic heart disease, a myocardial infarction or that were dispensed nitrate treatment as defined by items under sub-section 2.6.1 of the British National Formulary (BNF), because for those individuals we assumed that the heart failure was caused by the ischaemic heart disease.

In addition, a percentage[3] of the number of individuals that had a diagnosis of heart failure between 1 January 1996 to 31 December 2016, for whom we could not assign a specific cause[4] was added to the prevalent count of COPD with heart failure.

Using this method of identifying prevalent cases of COPD with heart failure, we estimated that there were approximately 6,100 individuals in the Scottish population suffering disability due to COPD with heart failure in 2016.

Severity distribution and disability weights

The levels of severity and disability due to COPD in Scotland were based on the specifications of the GBD 2016 study [11]. This allowed 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, condition and injury [12]. The severity distributions and disability weights for COPD and COPD with heart failure are outlined in Table 1and Table 2 below.

Once the severity of COPD and associated disability were taken into account, individuals were estimated to be suffering approximately 8,200YLDs due to living with COPD in Scotland in 2016.

[3] 9.6% of the cases, this is extracted from the worldwide prevalence estimates of heart failure according to the aetiology, published by GBD 2013 [15]

[4] ischaemic heart disease, COPD, hypertensive heart disease, cardiomyopathy and myocarditis, other cardiovascular and circulatory diseases, rheumatic heart disease, congenital heart anomalies, endocarditis, interstitial lung disease and pulmonary sarcoidosis, other haemoglobinopathies and haemolytic anaemias, iron-deficiency anaemia, other pneumoconiosis, thalassemias, silicosis, G6PD deficiency, iodine deficiency, Coal workers' pneumoconiosis, asbestosis and endocrine, metabolic, blood, and immune disorders.

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

Severity level	Description	% of individuals	Disability weight
Asymptomatic	Has condition but experiences no symptoms by virtue of, for instance being on treatment or because of the natural course of the condition.	53	0.000
Mild	Has cough and shortness of breath after heavy physical activity, but is able to walk long distances and climb stairs.	30	0.019
Moderate	Has cough, wheezing and shortness of breath, even after light physical activity. The person feels tired and can walk only short distances or climb only a few stairs.	7	0.225
Severe (without heart failure)	Has cough, wheezing and shortness of breath all the time. The person has great difficulty walking even short distances or climbing any stairs, feels tired when at rest, and is anxious.	9	0.408

Table 2 Description and allocation to severity levels for COPD with heart failure with corresponding disability weight

Severity level	Description	% of individuals	Disability weight
Mild	Is short of breath and easily tires with moderate physical activity, such as walking uphill or more than a quarter-mile on level ground. The person feels comfortable at rest or during activities requiring less effort.	55	0.041
Moderate	Is short of breath and easily tires with minimal physical activity, such as walking only a short distance. The person feels comfortable at rest but avoids moderate activity.	12	0.451
Severe	Is short of breath and feels tired when at rest. The person avoids any physical activity, for fear of worsening the breathing problems.	32	0.514

Data quality

In order to provide a measure of the degree of accuracy[5] and relevance[6] 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].

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

When estimating the burden of COPD, we have estimated that 83% of the burden is attributed to premature mortality due to TBLC. Since Scottish mortality data is deemed to be of high-quality [3], we are confident that our estimation of COPD YLL is highly accurate. In comparison, GBD2016 estimated that 84% of the COPD burden was caused by premature mortality.

[5] How precise, unbiased or certain the estimate is.
[6] Do we measure the thing we want to measure?

The contribution to the DALY from individuals still alive and living with COPD presents some issues. Our estimate of COPD prevalence in Scotland (2.4%) is based on a GP register of COPD cases [7] and these type of administrative datasets have been reported to underestimate the true prevalence of COPD, by as much as a third [13]. Furthermore, COPD diagnoses are probably only being established in the moderate to severe stages of the disease with under diagnosis is more likely in patients with mild disease than in those with severe disease (5% diagnosed versus 50% diagnosed respectively) [14].

Since COPD is a chronic disease we assumed that once somebody is diagnosed they will be a prevalent case until death. However, because PTI does not include information about mortality we estimated when that happens based on national averages and the excess mortality for COPD, adding another layer of uncertainty to our prevalence estimates.

It is therefore likely that we have underestimated the burden attributable to COPD. If we were to uplift our current prevalence estimate by approximately a third to account for undiagnosed COPD cases (and assume the same severity distribution as applied to diagnosed COPD cases) this would result in an additional 2800 YLD being generated. This would result in COPD being ranked as the sixth leading contributor disease burden compared to its current ranking of ninth.

What next to improve estimates for COPD?

Future work on the SBoD study will attempt to refine the estimates of prevalence. The improvement of prevalence estimates will include reviewing the coding and recording of COPD in alternative national datasets and explore local area datasets for information. The development of the Scottish Primary Care Information Resource (SPIRE) will help us to improve our estimates of the burden of disease in Scotland [15]. 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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