


# Scottish Burden of Disease Study, 2015

## Rheumatoid arthritis 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 2015 [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 rheumatoid arthritis in SBoD.

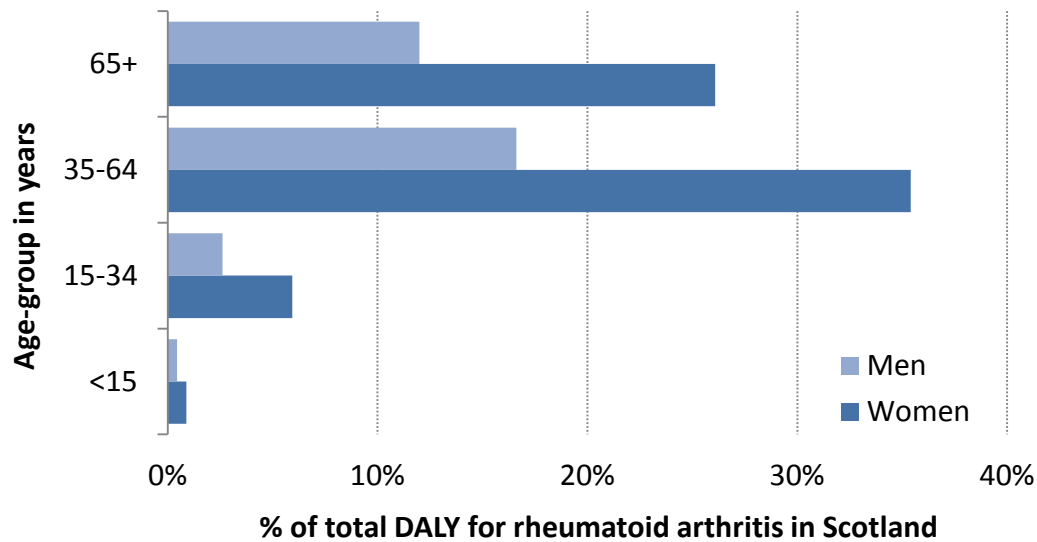
Burden of disease studies aim to estimate the difference between ideal and actual health in a country or region at a specific point in time. Individuals can suffer non-fatal health loss due to suffering disability attributable to a disease, condition or injury, or suffer fatal health loss which is early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

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 rheumatoid arthritis

Rheumatoid arthritis was the 23<sup>rd</sup> most common cause of disease burden in Scotland in 2015, resulting in a total of approximately 17,200 DALYs. Of this total burden, 7% was due to premature mortality attributed to rheumatoid arthritis and 93% was attributed to the health loss suffered due to living with rheumatoid arthritis.

**Figure 1 Percentage of total DALYs by gender and age group for rheumatoid arthritis**



Women contributed a higher proportion of the burden (68%) than men (32%). Overall, 52% of the total rheumatoid arthritis burden was contributed by individuals aged 35 to 64 years, as outlined in Figure 1. Note that the burden we are describing is the absolute burden and has not been adjusted for the age/gender case-mix.

## 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 rheumatoid arthritis

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 rheumatoid arthritis death from the expected remaining life expectancy for a person at that age.

### Estimating the number of deaths

There were a total of 110 deaths caused by rheumatoid arthritis in 2015. 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 rheumatoid arthritis 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. These ill-defined deaths are therefore redistributed amongst specific causes of death across the burden of disease cause list based on the redistribution of deaths method used in the GBD study [3]. For rheumatoid arthritis, approximately 3% of the death count comes from ill-defined death categories such as E85.4 'organ-limited amyloidosis' and other ICD-10 codes. Further explanation of this method is available in the SBoD technical paper [1]. For this reason, the number of deaths due to rheumatoid arthritis which have been reported are different from that of officially reported sources.

## **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 [5]. There were approximately 1,200 YLL due to rheumatoid arthritis in Scotland in 2015. Dividing the total YLL for rheumatoid arthritis by the total mortality count indicates that, on average, individuals who die due to rheumatoid arthritis die 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 rheumatoid arthritis**

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 number of individuals suffering disability**

To estimate prevalent cases of rheumatoid arthritis in 2015, the Practice Team Information dataset (PTI) was used [6]. 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 code using Read codes [7]. The number of individuals that had a Read code specific to rheumatoid arthritis between 1 April 2003 and 31 September 2013 were used to estimate prevalence. We used a list of Read codes developed by Keele University to identify rheumatoid arthritis prevalent cases [8]. Individuals that attended their GP and consulted for rheumatoid arthritis for the first time were counted in the yearly incidence, and we assumed that they remain a prevalent case until the point of death. We projected the estimated annual incidence trends of rheumatoid arthritis for the time period covered by PTI (2003-2013) to 2014 and 2015. The estimated incidence and mortality data was used to calculate 2015 prevalence. There is no information about the death of individuals in PTI, so adjustments to account for deaths were made using average age and gender specific mortality rates in Scotland.

Using this method of identifying prevalent cases of rheumatoid arthritis, we estimated that there were approximately 68,600 individuals in the Scottish population living with rheumatoid arthritis in 2015.

### **Severity distribution and disability weights**

The levels of severity and disability due to rheumatoid arthritis in Scotland were based on the specifications of the GBD 2015 study [9]. 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 [10]. The severity distributions and disability weights for rheumatoid arthritis are outlined in Table 1.

Once the severity of rheumatoid arthritis and associated disability were taken into account, individuals were estimated to be suffering approximately 16,000 YLDs due to rheumatoid arthritis in Scotland in 2015.

**Table 1 Description and allocation to severity levels for rheumatoid arthritis with corresponding disability weight**

<b>Severity level</b>	<b>Description</b>	<b>% of individuals</b>	<b>Disability weight</b>
Mild	Has moderate pain and stiffness in the arms and hands, which causes difficulty lifting, carrying, and holding things, and trouble sleeping because of the pain.	50	0.117
Moderate	Has pain and deformity in most joints, causing difficulty moving around, getting up and down, and using the hands for lifting and carrying. The person often feels fatigue.	38	0.317
Severe	Has severe, constant pain and deformity in most joints, causing difficulty moving around, getting up and down, eating, dressing, lifting, carrying and using the hands. The person often feels sadness, anxiety and extreme fatigue.	12	0.581

## Data quality

In order to provide a measure of the degree of accuracy<sup>1</sup> and relevance<sup>2</sup> 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:

<sup>1</sup> How precise, unbiased or certain the estimate is.

<sup>2</sup> Do we measure the thing we want to measure?

### **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. These estimates can be considered a highly accurate depiction of the burden incurred from the disease, condition or injury.

### **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. These estimates can be considered a moderately accurate depiction of the burden incurred from the disease, condition or injury.


### **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. These estimates contain substantial uncertainties and should be used with some caution.

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 rheumatoid arthritis in Scotland are  **moderately accurate and relevant.**

The burden of rheumatoid arthritis is mostly driven by our prevalence estimates. There are no national registries available for rheumatoid arthritis; hence we used primary care data. Rheumatoid arthritis is a chronic disease, so 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 used general Scottish mortality rates. While mortality may be increased in rheumatoid arthritis [11], we could not apply this excess mortality to our estimates because we are not aware of any study that quantifies it. However this likely excess mortality means that our method would lead to an over-estimate of true prevalence.

We estimated that there were approximately 68,600 individuals living with rheumatoid arthritis in Scotland in 2015. The GBD 2015 estimated that there were 40,200 individuals [12]. Arthritis Research UK estimates a prevalence of 43,700 individuals<sup>3</sup>. This estimate is obtained by modelling the rheumatoid arthritis cases<sup>4</sup> in the English Longitudinal Study of Ageing using socio-demographic, lifestyle and other factors [13] and extrapolating the results to the Scottish population. The Quality and Outcomes Framework [14] started collecting data on rheumatoid arthritis in 2013, and reported a prevalence estimate of 34,000 for the financial year 2015/16, an increase of 6% from the number of cases reported in the financial year 2013/2014.

Our men/women prevalence ratio is 1:2.2, which is lower than the 1:2.7 men/women prevalence ratio reported by other studies [15]. It's likely that rheumatoid arthritis cases are misclassified in the PTI dataset and some of them correspond to other musculoskeletal diseases, which have a lower men/women prevalence ratio. Our use of general population mortality and the fact that other prevalence estimates for the UK [15] and other European countries [16] are lower than ours are indications that we may have over-estimated the burden of rheumatoid arthritis.

## **What next to improve estimates for rheumatoid arthritis?**

Future work on the SBoD study will attempt to refine the estimates of prevalence. This work will include reviewing the coding and recording of rheumatoid arthritis in alternative national datasets and exploring local area datasets for information. The

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<sup>3</sup> Personal communication

<sup>4</sup> Prevalent cases in the English Longitudinal Study of Ageing are those reporting that the doctor has diagnosed them as having rheumatoid arthritis

development of the Scottish Primary Care Information Resource (SPIRE) will help us to improve our estimates of the burden of disease in Scotland [17]. 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. Additionally, we hope to be able to link prevalent cases with information about the vital status of the individual to obtain a more accurate estimate.

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](mailto:nhs.healthscotland-sbod-team@nhs.net)) for enquiries and suggestions on how to improve our estimates.

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