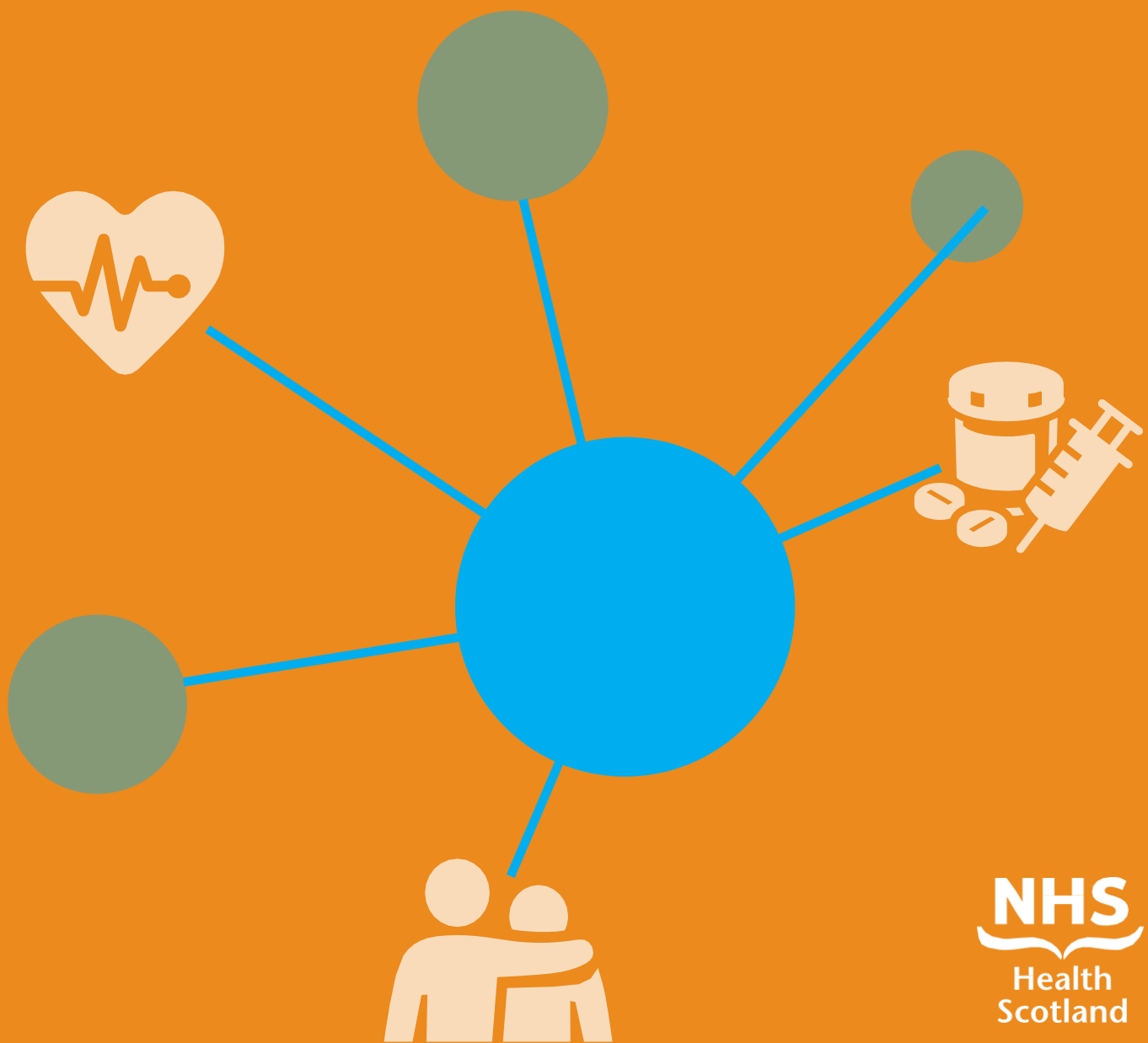# The Scottish Burden of Disease Study, 2016

Alzheimer's disease and other dementias technical overview

This resource may also be made available
on request in the following formats:

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 Alzheimer's disease and other dementias (ADOD) 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 Alzheimer's and other dementias

ADOD were the 6th most common cause of disease burden in Scotland in 2016, resulting in a total of approximately 48,989 DALYs. Of this total burden, 78% was due to the fatal burden of ADOD, with 22% being attributed to the non-fatal burden.

Figure 1 Percentage of total DALYs by gender and age-group for ADOD
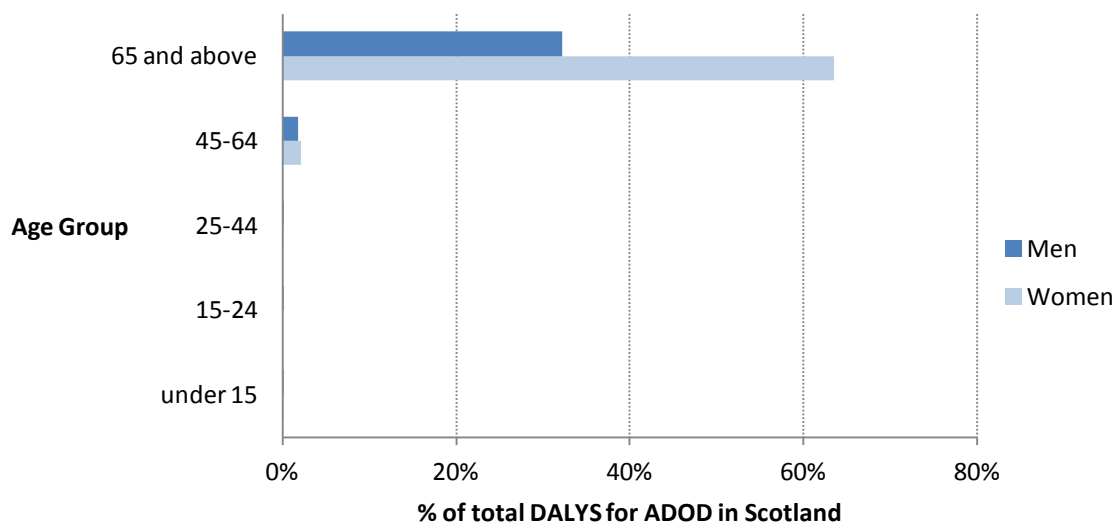
Women contributed a higher proportion of the burden (66%) than men (34%). Overall, 96% of the total ADOD burden was contributed by individuals aged 65 years and over, as outlined in Figure 1. Women in this age group contributed a higher proportion (64%%) to the total ADOD burden than men (32%).Note that 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, by deprivation[1] decile for AOD are shown in Figure 2. The highest DALY rates were found in the 20% most deprived deciles (decile 1 and 2) and the lowest in the 10% least deprived decile(decile 10).

Figure 2 DALY (rates per 100,000[2]) of total ADOD burden by deprivation decile
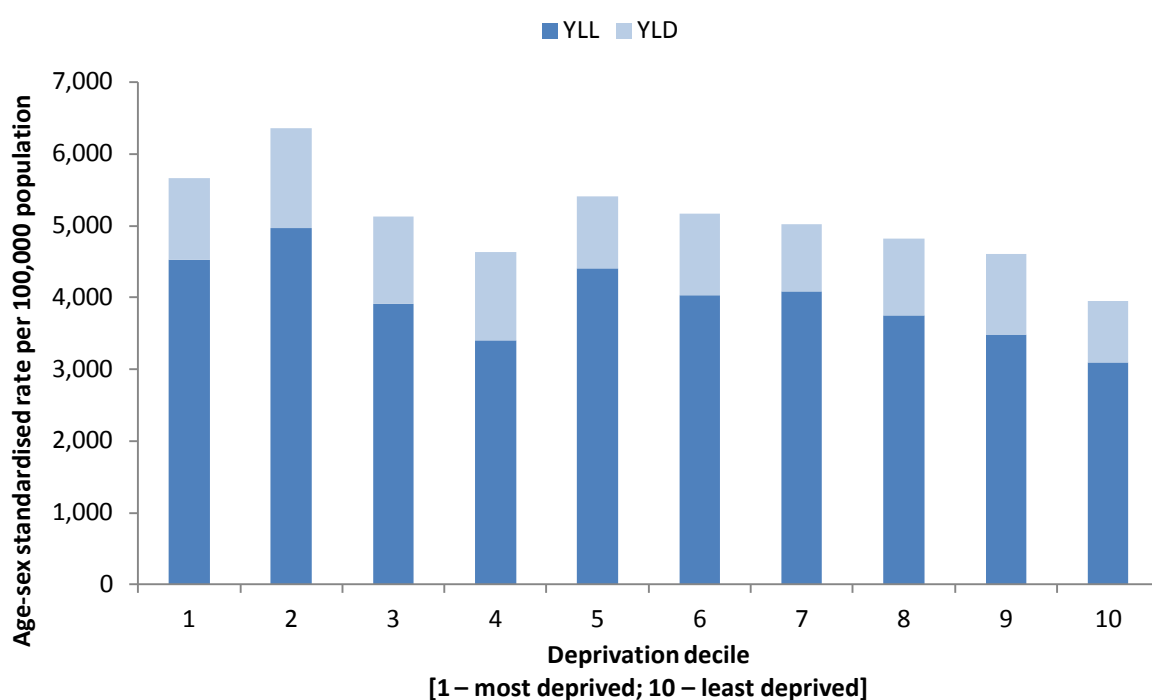
How did we produce these estimates?

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).

---

[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.

Years of life lost (YLL) to Alzheimer's and other dementias

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 ADOD 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 5,600 deaths per year caused by ADOD. 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 ADOD 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 individual's clinical history was evaluated to inform the target cause for redistribution. For ADOD, approximately 2% of the mortality count comes from these ill-defined deaths. For this reason, the number of deaths due to ADOD 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 38,000 YLL due to ADOD in Scotland in 2016. Dividing the total YLL for ADOD by the total mortality count indicates that, on average, individuals who die due to ADOD die approximately 6 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 Alzheimer's and other dementias

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 number of individuals suffering disability

To estimate prevalent cases of ADOD in 2016, the Practice Team Information dataset (PTI) was used [7]. 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 [8]. The number of individuals that had a Read code specific to ADOD, between 1 April 2003 and 31 September 2013, were used to estimate prevalence. Individuals were counted once in any year in which they attended their GP and consulted for ADOD. We projected the estimated annual incidence trends of ADOD, censoring for mortality, for the time period (2003-2013) to estimate the number of prevalent cases in 2016. There is no information about the death of individuals in PTI, so adjustments to account for deaths were made using average mortality rates for each age, gender and deprivation decile in Scotland and the age-sex specific excess mortality rates for ADOD as defined in GBD 2016 [9].

Using this method of identifying prevalent cases of ADOD, we estimated that there were approximately 66,000 individuals in the Scottish population suffering disability due to ADOD in 2016.

Severity distribution and disability weights

The levels of severity and disability due to ADOD in Scotland were based on the specifications of the GBD 2016 study [10]. 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 [11]. The severity distribution and disability weights for ADOD are outlined in Table 1.

Once the severity of ADOD and associated disability were taken into account, individuals were estimated to be suffering approximately 11,000 YLDs in 2016 due to living with ADOD.

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

Severity level	Description	% of individuals	Disability weight
Mild	Has some trouble remembering recent events, and finds it hard to concentrate and make decisions and plans.	68	0.069
Moderate	Has memory problems and confusion, feels disoriented, at times hears voices that are not real, and needs help with some daily activities.	22	0.377
Severe	Has complete memory loss; no longer recognizes close family members; and requires help with all daily activities.	10	0.449

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:

�Ⓡ Ⓐ 🟢 **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.

---

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

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 ADOD in Scotland are Ⓡ Ⓐ Ⓖ **moderately accurate and relevant**

When estimating the burden of ADOD, we have estimated that over three quarters (78%) of the burden is attributed to premature mortality due to ADOD. Scottish mortality data is deemed to be of high-quality, which is the main reason for this assessment [3].

The Global Burden of Disease study (GBD) 2016 estimated an ADOD prevalence of 1.4% in Scotland in 2016 [12]. Alzheimer's Scotland estimate a prevalence of 1.7% which is based on a composite of age-specific rates from findings from two previous studies [13, 14] that were applied to Scottish population estimates. Our prevalence estimate of 1.2% is lower than both the GBD 2016 and Alzheimer's Scotland estimates. We have chosen to use GP consultations to determine the number of patients that suffer disability due to ADOD, for which we have a decade of patient-consultation data however diagnosis in primary care is dependent on clinical suspicion, or suspicions from carers, meaning that there is a possibility of bias due to of missed diagnoses. The true prevalence of missed and delayed diagnoses of dementia is unknown but appears to be high [15]. Based on primary care data, tt is estimated that 26% of dementia cases are undiagnosed in Scotland [16]. If we apply this proportion to our current prevalence estimate this would give a prevalence of approximately 83,500 (from 66,300) and an additional 3000 YLD. This would lead to ADOD being the fourth leading contributor of disease burden in Scotland, compared to its current rank of sixth.

However, we also may be underestimating excess mortality in individuals with ADOD. To account for excess mortality, we used estimates from GBD 2016. As Scotland has a lower life expectancy than is used in the GBD 2016 study, the probability of death will be higher at younger ages in Scotland than it would be from the GBD 2016 study. However, we have insufficient data or evidence to try to refine our estimates. The effect that this will have means that excess mortality in individuals with ADOD is only partially accounted for when using estimates derived from PTI, which will result in an overestimate of YLD.

What next to improve estimates for Alzheimer's and other dementias?

Future work on the SBoD study will attempt to refine the estimates of prevalence. This work will include reviewing the coding and recording of ADOD in alternative national datasets and exploring surveys and 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 [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.

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

[1] Scottish Burden of Disease study. Scottish Public Health Observatory, Available from: URL: http://www.scotpho.org.uk/comparative-health/burden-of-disease/overview (Accessed 30 July 2018).

[2] National Records of Scotland (NRS). Vital Events - Deaths. Scottish Government, Available from: URL: https://www.nrscotland.gov.uk/statistics-and-data/statistics/statistics-by-theme/vital-events/deaths (Accessed 30 July 2018).

[3] GBD 2016 Causes of Death Collaborators. Global, regional, and national age-sex specific mortality for 264 causes of death, 1980–2016: a systematic analysis for the Global Burden of Disease Study 2016. Lancet 2017; 390: 1151–210.

[4] World Health Organization. International Statistical Classification of Diseases and Related Health Problems 10th Revision (ICD-10) Version for 2010, Geneva. World Health Organization, Available from: URL: http://apps.who.int/classifications/icd10/browse/2010/en (Accessed 30 July 2018).

[5] Scotland's population – The Registrar General's Annual Review of Demographic Trends, Scotland. National Records of Scotland, 2017, Available from: URL: https://www.nrscotland.gov.uk/statistics-and-data/statistics/stats-at-a-glance/registrar-generals-annual-review (Accessed 30 July 2018).

[6] Office for National Statistics. National Life Tables: Scotland. Open Government Licence, Available from: URL: https://www.ons.gov.uk/peoplepopulationandcommunity/birthsdeathsandmarriages/lifeexpectancies/datasets/nationallifetablesscotlandreferencetables (Accessed 30 July 2018).

[7] ISD Scotland. Practice Team Information. NHS National Services Scotland, Available from: URL: http://www.isdscotland.org/Health-Topics/General-Practice/PTI-Support/ (Accessed 30 July 2018).

[8] NHS Digital. Read Codes. NHS Digital, Available from: URL: https://digital.nhs.uk/article/1104/Read-Codes (Accessed 30 July 2018).

[9] Supplement to GBD 2016 Disease and Injury Incidence and Prevalence Collaborators Global, regional, and national incidence, prevalence, and years lived with disability for 328 diseases and injuries for 195 countries, 1990–2016: a systematic analysis for the Global Burden of Disease Study 2016. Lancet, 2017 390, 1211-1259.

[10] GBD 2016 Disease and Injury Incidence and Prevalence Collaborators Global, regional, and national incidence, prevalence, and years lived with disability for 328 diseases and injuries for 195 countries, 1990–2016: a systematic analysis for the Global Burden of Disease Study 2016. Lancet, 2017 390, 1211-1259.

[11] Salomon JA, Haagsma JA, Davis A, de Noordhout CM, Polinder S, Havelaar AH, et al. Disability weights for the Global Burden of Disease 2013 study. The Lancet Global Health 2015 Nov;3(11):e712-e723.

[12] Institute for Health Metrics and Evaluation (IHME). GBD Results Tool. Seattle, WA: IHME, University of Washington. Available from: URL: http://ghdx.healthdata.org/gbd-results-tool (Accessed 30 July 2018).

[13] Harvey R. Young onset dementia: epidemiology, clinical symptoms, family burden, support and outcome. Imperial College London. 1998.

[14] Alzheimer Europe. EuroCoDe: prevalence of dementia in Europe. Alzheimer Europe, Available from: URL: https://www.alzheimer-europe.org/Research/European-Collaboration-on-Dementia/Prevalence-of-dementia/Prevalence-of-dementia-in-Europe (Accessed 30 July 2018).

[15] Bradford A, Kunik ME, Schulz P, Williams SP, Singh H. Missed and Delayed Diagnosis of Dementia in Primary Care: Prevalence and Contributing Factors. Alzheimer Dis Assoc Disord 2009 Oct;23(4):306-14.

[16] Alzheimer's Research UK, Available from: URL: https://www.dementiastatistics.org/statistics/diagnoses-in-the-uk/ (Accessed 30 July 2018).

[17] Scottish Primary Care Information Resource (SPIRE). NHS National Services Scotland, Available from: URL: http://spire.scot/ (Accessed 30 July 2018).

6519 8/2018