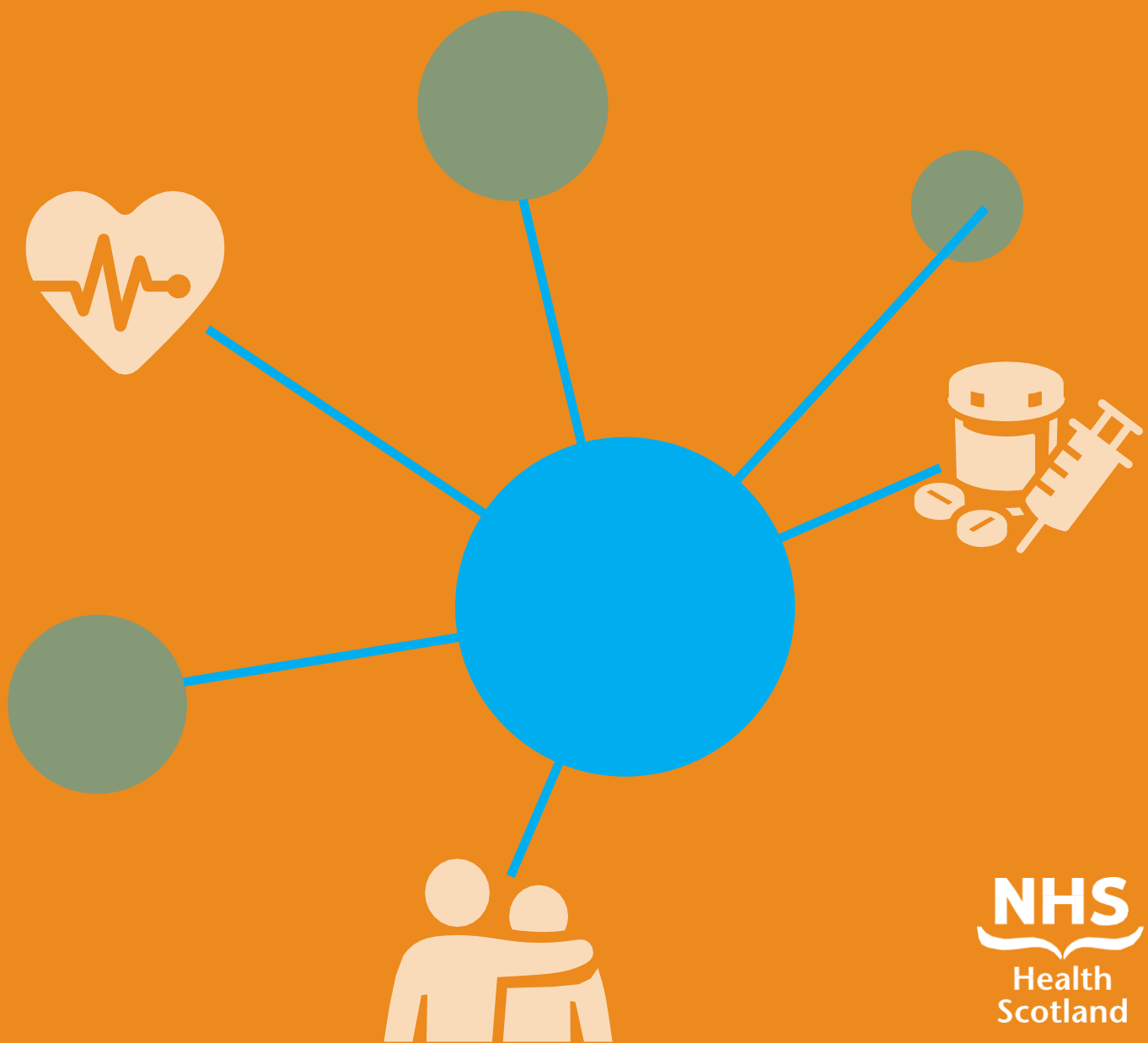



The Scottish Burden of Disease Study, 2016

Sense organ diseases 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 sense organ diseases in SBoD. The diseases that are grouped under sense organ diseases are:

- Cataracts
- Glaucoma
- Macular degeneration
- Refraction and accommodation disorders
- Other vision loss, this category refers to disease causing vision loss, excluding those already covered in the GBD disease list [2]
- Age-related and other hearing loss, excluding hearing loss caused by any of the diseases in the GBD disease list [2]
- Other sense organ diseases, this is a residual category capturing a variety of both acute and chronic conditions that do not map to other causes, but lead to non-trivial morbidity.

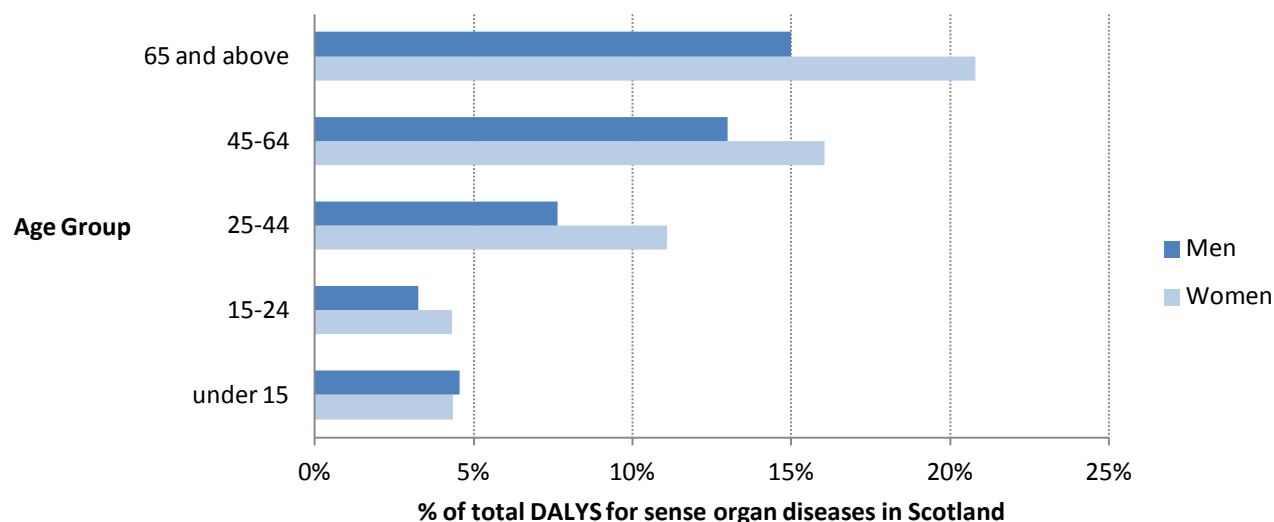
Burden of disease studies aim to estimate the difference between ideal and actual health in a country or region at a specific point in time. Individuals can suffer non-fatal health loss due to suffering disability attributable to a disease or injury, or suffer fatal health loss which is early death due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

Sense organ diseases are the 11th most common cause of disease burden in Scotland in 2016, resulting in a total of approximately 43,200 DALYs. The burden of sense organ diseases is fully attributed to individuals suffering health loss due to living with sense organ diseases.

Figure 1 Percentage of total DALY by gender and age-group for sense organ diseases



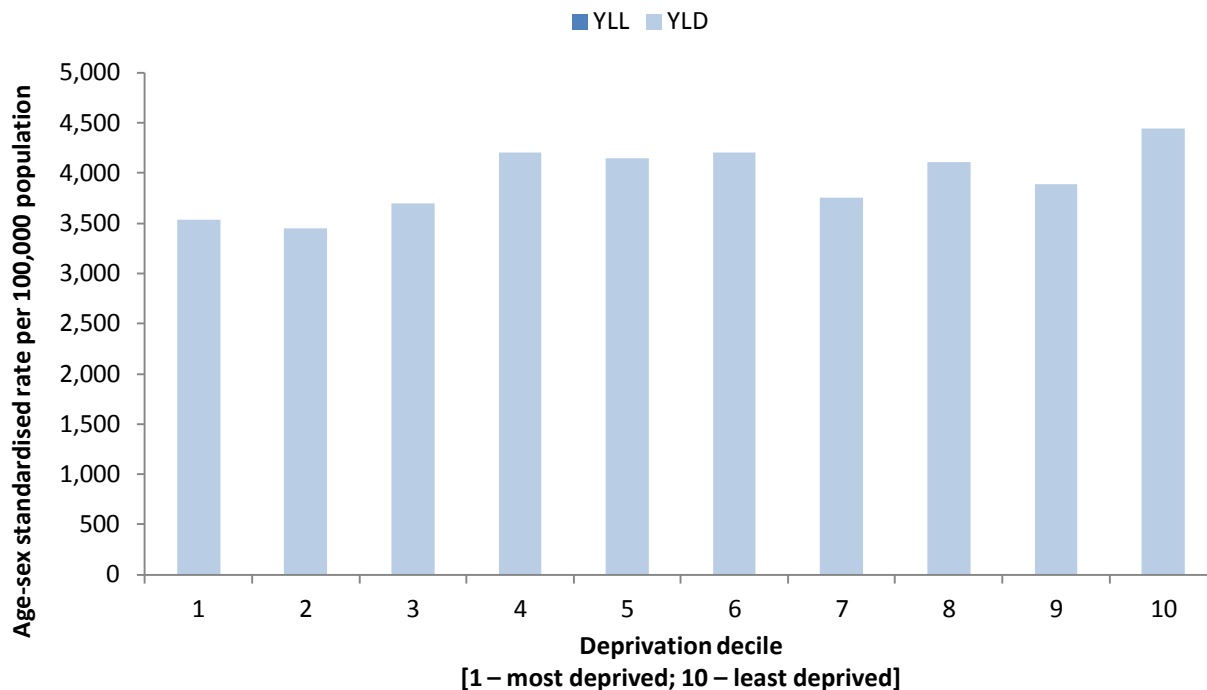
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Men and women contributed a 43%, while women contributed 57% to the burden of sense organ diseases. Overall, 36% of the total sense organ diseases burden was contributed by individuals aged 65 years and over, as outlined in Figure 1. Women aged 65 years over contributed the highest proportion (21%) to the total sense organ diseases burden, followed by women aged 45-64 years (16%) and men aged 65 years and over (15%). 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 sense organ diseases, by deprivation¹ decile, are shown in Figure 2. DALYs remained relatively stable across levels of deprivation: the age standardised rate peaks in the least deprived decile and it is the lowest for the first and the second most deprived deciles.

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.

Figure 2 DALYs (rates per 100,000²) for total sense organ disease burden by deprivation decile



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 sense organ diseases

Each single death contributes to the total YLL through calculating the difference between the age at death and the life expectancy at that age. Sense Organ diseases are not regarded, in itself, as valid causes of death in burden of disease studies [2]. There is, therefore, no YLL component in the DALY for this condition; the entire burden estimated comes from non-fatal consequences of health loss due to sense organ diseases.

Years Lived with Disability (YLD) due to sense organ diseases

Years lived with disability (YLD) are estimated using:

- disease and injury prevalence estimates
- levels of severity
- disability weights

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.

Our sources of information for these three components were as follows:

Estimating the number of individuals suffering disability

We used a different data source to estimate prevalent cases of each of the diseases that are part of sense organ diseases. This ensures that we used the data source that most likely records an individual contact with the health service.

Cataracts, glaucoma, macular degeneration and other vision loss

To estimate cases of cataracts, glaucoma, macular degeneration and other vision loss in 2016, we used secondary care data. We linked the multiple datasets that make up the Scottish Morbidity Records (SMRs), including outpatient's appointment, into a single dataset using the Community Health Index (CHI) number. SMRs have a CHI number attached to the hospital episode of care, which allows for the identification of records for an individual. The CHI number attached to each record has allowed us to source records from the National Records of Scotland (NRS) register of deaths, to exclude individuals that have died from estimates following their date of death. Additionally, SMRs contain structured data in the form of International Statistical Classification of Disease (ICD-10) [3] 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 refer to co-morbidities that may affect care during that episode of care. Our estimates make use of all available codes. We used the list of ICD-10 codes reported by the GBD 2016 study [2].

The number of individuals that had a diagnosis of glaucoma, macular degeneration or other vision loss disease between 1 January 1996 to 31 December 2016, and who were still alive at the end of 2016, were used to estimate the number of prevalent cases in 2016. This period was used because we set 20 years as the standard follow-up period for life-long diseases.

For cataracts, we used the number of individuals in contact with the health services in a secondary care setting in 2016, with a diagnosis of cataracts or with a record indicating that they underwent a procedure related to cataracts (OPCS-4 codes C71-C75) as a measure of prevalence. This assumes that the condition is diagnosed or treated in secondary care, that the condition is not chronic, that surgery is an effective treatment and that the individual does not have to wait longer than a year to undergo surgery.

For the case of other vision loss, we excluded individuals who had a diagnosis of a set of diseases³ at any point in their life. This is because vision loss is a sequelae of these diseases, hence the burden of vision loss for these individuals is accounted for when we considered the burden of these specific diseases.

³ Meningitis, encephalitis, preterm birth complications, diabetes mellitus, sepsis and other infectious disorders of the newborn baby, haemolytic disease in foetus and newborn and other neonatal jaundice, cataracts, glaucoma and macular degeneration.

Other sense organ diseases

To estimate prevalent cases of other sense organ diseases in 2016, the Practice Team Information dataset (PTI) was used [4]. 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 [5]. We further classified other sense organ diseases as having either short term or long term outcomes. We assumed that consultations related to short term outcomes of other sense organ diseases identify acute cases only, that is the individual suffers the condition for a short period of time. In contrast, we assumed that consultations related to long term outcomes of other sense organ diseases identify chronic problems.

The number of individuals that had a Read code [5] specific to a chronic form of other sense organ diseases between 1 April 2003 and 31 September 2013 were used to estimate prevalence. The list of Read codes we used to identify both acute and chronic forms of other organ diseases can be found in the technical report on the ScotPHO website [1]. Individuals that attended their GP and consulted for chronic other sense organ diseases for the first time were counted in the annual incidence, and we assumed that they remained a prevalent case until the point of death. We projected the estimated annual incidence trends of chronic other sense organ diseases for the period covered by PTI (2003-2013) to 2014, 2015 and 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. In addition, we estimated the burden of the acute form of other sense organ diseases by extrapolating the average number of consultations for the period 2003-2013 to 2016 and assuming that the average duration to recover from these diseases is seven days. That is if the same individual consulted twice or more in a week, we counted it as one acute event.

Age-related and other hearing loss

To estimate the prevalence of age-related and other hearing loss we used the results of the Health Survey for England (HSE) 2014 [6]. The hearing loss module reports on the results of a test with a HearCheck screening device conducted by nurses. We used the English prevalence estimates for the tests performed at 3 KHz, but applied a correction factor of 0.95. This correction factor takes into account the fact that hearing loss is a sequelae of some severity levels of the following diseases: otitis media, meningitis and congenital anomalies, hence the burden of hearing loss is already counted in these diseases and should not be included here. We extracted this correction factor from SMRs, by counting the percentage of individuals with a diagnosis from one of these diseases from the total number of individuals with a diagnosis of age-related and other hearing loss at any point in their life.

Refraction and accommodation disorders

To estimate the prevalence of refraction and accommodation disorders we used data collected by eye care providers and submitted to the Practitioner Services [7]. Data from these submissions is published by the NHS General Ophthalmic Services [8]. We used the reported number of diagnosis for binocular vision anomaly, corrected refractive error or rapidly progressing myopia to estimate the number of people suffering from refraction and accommodation disorders in a given year. Data submitted by eye care providers is of low quality and in most cases does not have a personal identifier, hence it is likely that there is double-counting of individuals. A small percentage of records contain personal information and postcode information. We use the information in these records to infer the age groups, gender and deprivation group of those affected by refraction and accommodation disorders.

Table 1 presents the number of individuals (or consultations for the short term outcomes of other sense organ diseases) in the Scottish population suffering disability due to sense organ diseases in 2016.

Table 1 Number of consultations or individuals affected by sense organ diseases subgroups in Scotland, 2016

Disease or condition	Individuals	Consultations
Cataracts	35,500	n/a
Glaucoma	15,400	n/a
Refraction disorders	396,000	n/a
Other hearing loss	580,800	n/a
Macular degeneration	13,400	n/a
Other vision loss	44,600	n/a
Other sense organ diseases acute	n/a	385,800
Other sense organ diseases chronic	406,200	n/a

Severity distribution and disability weights

The levels of severity and disability due to sense organ diseases in Scotland were based on the specifications of the GBD 2016 study [2]. 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 [9]. The severity distributions and disability weights for sense organ diseases are outlined in Table 2 and Table 3.

Table 2 Severity levels for each of the subgroups of sense organ diseases with corresponding severity distribution

Disease	Severity level	% of individuals
Cataracts	Moderate vision impairment	69
	Severe vision impairment	16
	Blindness	14
Macular degeneration	Moderate vision impairment	72
	Severe vision impairment	13
	Blindness	16
Glaucoma	Moderate vision impairment	49
	Severe vision impairment	10
	Blindness	41
Other vision loss	Moderate vision impairment	66
	Severe vision impairment	11
	Blindness	23
Age-related and other hearing loss without and with ringing	Mild hearing loss due to age-related and other hearing loss	56
	Mild hearing loss with ringing due to age-related and other hearing loss	15
	Moderate hearing loss due to age-related and other hearing loss	14
	Moderate hearing loss with ringing due to age-related and other hearing loss	6
	Moderately severe hearing loss due to age-related and other hearing loss	5
	Moderately severe hearing loss with ringing due to age-related and other hearing loss	2
	Severe hearing loss due to age-related and other hearing loss	1
	Severe hearing loss with ringing due to age-related and other hearing loss	<1
	Profound hearing loss due to age-related and other hearing loss	<1
	Profound hearing loss with ringing due to age-related and other hearing loss	<1
	Complete hearing loss due to age-related and other hearing loss	<1
	Complete hearing loss with ringing due to age-related and other hearing loss	<1
	Other sense organ diseases	Aysmptomatic
Moderate		16
Severe		30
Refraction and accommodation disorders	Near vision impairment	100

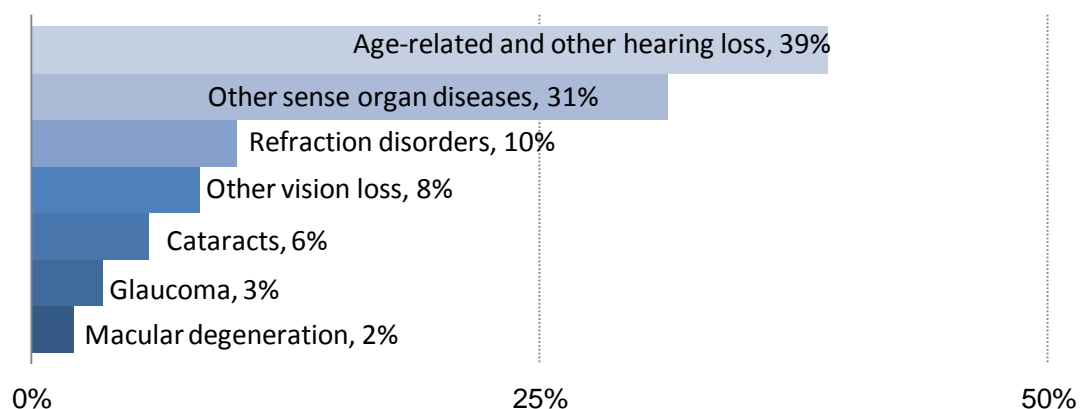
Table 3 Description of severity levels for sense organ diseases with corresponding disability weight given by the GBD 2015 study

Severity level	Description	Disability weight
Near vision impairment	has difficulty seeing things that are nearer than 3 feet, but has no difficulty with seeing things at a distance.	0.011
Moderate vision impairment	Has vision problems that make it difficult to recognize faces or objects across a room.	0.031
Severe vision impairment	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.	0.184
Blindness	Is completely blind, which causes great difficulty in some daily activities, worry and anxiety, and great difficulty going outside the home without assistance.	0.187
Mild hearing loss	Has great difficulty hearing and understanding another person talking in a noisy place (for example, on an urban street)	0.010
Mild hearing loss with ringing	Has great difficulty hearing and understanding another person talking in a noisy place (for example, on an urban street), and sometimes has annoying ringing in the ears.	0.021
Moderate hearing loss	Is unable to hear and understand another person talking in a noisy place (for example, on an urban street), and has difficulty hearing another person talking even in a quiet place or on the phone.	0.027
Moderate hearing loss with ringing	Is unable to hear and understand another person talking in a noisy place (for example, on an urban street), has difficulty hearing another person talking even in a quiet place or on the phone, and has annoying ringing in the ears for 5 minutes at a time, almost every day.	0.074
Moderately severe hearing loss	No definition provided	0.093
Moderately severe hearing loss with ringing	No definition provided	0.168
Severe hearing loss with ringing	Is unable to hear and understand another person talking, even in a quiet place, is unable to take part in a phone conversation, and has annoying ringing in the ears for more than 5 minutes at a time, almost every day. Difficulties with communicating and relating to others cause emotional impact at times (for example worry or depression).	0.261
Severe hearing loss	Is unable to hear and understand another person talking, even in a quiet place, and unable to take part in a phone conversation. Difficulties with communicating and relating to others cause emotional impact at times (for example worry or depression).	0.158
Profound hearing loss	Is unable to hear and understand another person talking, even in a quiet place, is unable to take part in a phone conversation, and has great difficulty hearing anything in	0.204

Severity level	Description	Disability weight
	any other situation. Difficulties with communicating and relating to others often cause worry, depression or loneliness.	
Profound hearing loss with ringing	Is unable to hear and understand another person talking, even in a quiet place, is unable to take part in a phone conversation, has great difficulty hearing anything in any other situation, and has annoying ringing in the ears for more than 5 minutes at a time, several times a day. Difficulties with communicating and relating to others often cause worry, depression, or loneliness.	0.277
Complete hearing loss	Cannot hear at all in any situation, including even the loudest sounds, and cannot communicate verbally or use a phone. Difficulties with communicating and relating to others often cause worry, depression or loneliness.	0.215
Complete hearing loss with ringing	Cannot hear at all in any situation, including even the loudest sounds, and cannot communicate verbally or use a phone, and has very annoying ringing in the ears for more than half of the day. Difficulties with communicating and relating to others often cause worry, depression or loneliness.	0.316

Once the severity of sense organ diseases and associated disability were taken into account, individuals were estimated to be suffering approximately 43,200 YLDs due to living with sense organ diseases. Figure 2 shows the distribution of the full burden amongst the disease subgroups: age-related and other hearing loss accounts for more than one-third of total DALYs, followed closely by other sense organ diseases

Figure 2 Percentage of total DALYs by disease subgroups within other sense organ diseases



Data quality

In order to provide a measure of the degree of accuracy⁴ and relevance⁵ 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 sense organ diseases in Scotland are  **moderately accurate and relevant.**

⁴ How precise, unbiased or certain the estimate is.

⁵ Do we measure the thing we want to measure?

Our figure of 43,200 DALYs is broadly comparable with the 46,100 DALYs estimated by the GBD 2016 [10]. However, we believe this is probably an overestimate, mostly driven by the estimated burden of other sense organ diseases. As we have used different data sources to estimate the burden of each condition we can't remove duplicated cases when the same condition is diagnosed or treated by multiple health care providers, namely eye care professionals, primary care or secondary care. Additionally, we have estimated the burden of refraction and accommodation disorders based on consultations, which again are likely to include duplicated counts, and we have assumed that this condition causes a burden for a whole year. This is unlikely to be the case, although we were unable to find relevant research that could provide a valid estimate.

More than one third of the burden of sense organ diseases comes from the results of HSE. While in itself this is a highly accurate and relevant data source, the lack of information about the cause of hearing loss forces us to use a correction factor for double counting burden across diseases, and adds a layer of uncertainty. In addition, there are differences in the survey results between regions of England, which highlights that Scotland may not closely reflect the average for England.

Our estimates for macular degeneration, cataract and glaucoma are from a relevant data source, SMR, and most likely gave us the lowest bound of these conditions, as diagnosis of these diseases does not usually happen in secondary care [11]. Our estimate for these conditions is 1,700 YLD higher than the estimated reported by GBD 2016. The ISD Scotland publication General Ophthalmic Services Statistics [12] reports on the number of consultations for cataracts, glaucoma and macular degeneration done by eye care professionals. These numbers cannot easily be translated to individuals but suggest a higher prevalence count than we estimated. Because of this limitation in identifying individuals in the data submitted by eye care professionals, we used SMR instead.

Our estimate for other vision loss is higher than that of the GBD 2016 and it's likely to be an over estimate, as some individuals may have already been counted in refraction and accommodation disorders, or they may, at the same time, suffer from glaucoma, macular degeneration or cataracts, so the burden caused by vision loss is counted twice.

Finally, we estimated other sense organ diseases from PTI; however this dataset is only a 5% sample of GP practices in Scotland. Most of the burden of other sense organ diseases comes from the long term outcomes for these diseases, that is, the assumption 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 sense organ diseases, adding uncertainty to our prevalence estimates.

What next to improve estimates for sense organ diseases?

Future work on the SBOD study will attempt to refine the estimates of prevalence. The data process to collect and record information about General Ophthalmic Services is currently under review to include CHI number; this will allow a better estimate of diseases related to vision loss. The development of the Scottish Primary Care Information Resource (SPIRE) will help us to improve our estimates of the burden of disease in Scotland [13], as well as exploring local area datasets and reviewing evidence from high quality research. 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.

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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