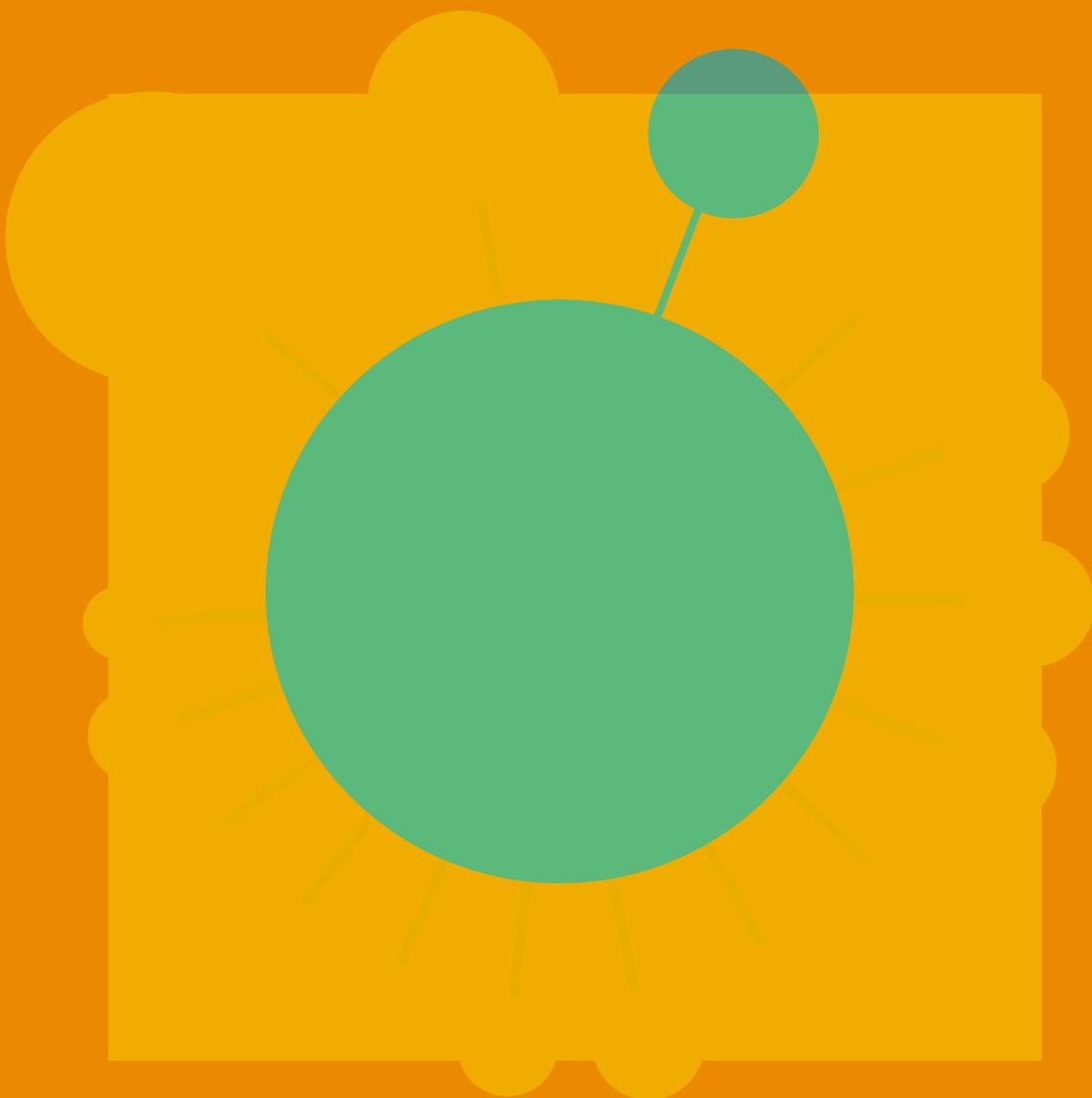


# Scottish Burden of Disease Study, 2015

## Breast cancer 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 breast cancer 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 breast cancer

When considering only the population of women<sup>1</sup>, breast cancer was the 10<sup>th</sup> most common cause of disease burden in Scotland in 2015, resulting in a total of approximately 19,800 DALYs. For the total population, breast cancer was the 20<sup>th</sup> most common cause of disease burden. Of this total burden, 88% was due to premature mortality attributed to breast cancer and 12% was attributed to the health loss suffered due to living with breast cancer.

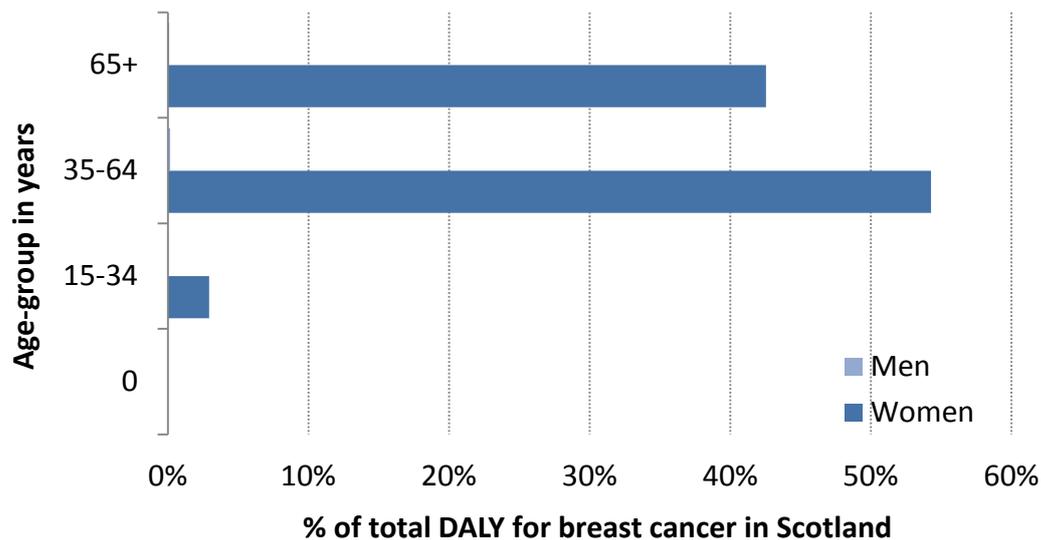
Men contributed 0.25% of the total burden of breast cancer. Overall, 54% of the total breast cancer burden was contributed by women aged 35 to 64

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<sup>1</sup> 0.5% of the breast cancer prevalent cases correspond to men. These have been included in the total DALYs for ranking the disease.

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.

**Figure 1 Percentage of total DALYs by age-group for breast cancer in women only**



## 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 breast cancer

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 breast cancer death from the expected remaining life expectancy for a person at that age.

### Estimating the number of deaths

There were a total of 1,087 deaths caused by breast cancer in 2015. These deaths were identified from the underlying cause of death on the National Records of Scotland (NRS) register of deaths [2] and the Global Burden of Disease 2015 cause list, which has been classified using the International

Statistical Classification of Diseases and Related Health Problems (ICD) [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 breast cancer mortality count are deaths that have come from what are termed ill-defined death groups 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. 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 breast cancer, 8.7% of the total death count comes from ill-defined death categories (such as C76 'malignant neoplasm of other and ill-defined sites' 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 breast cancer which have been reported are different from that of officially reported sources.

### **Years of life lost (YLL) due breast cancer**

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 17,400 YLL due to breast cancer in Scotland in 2015. Dividing the total YLL for breast cancer by the total number of deaths indicates that, on average, women who die due to breast cancer die 16 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 breast cancer

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 breast cancer in 2015, we used individual level data from the Scottish Cancer Registry and linked it to the NRS Register of Deaths using the Community Health Index (CHI). The linkage of datasets allowed us to identify individuals that were still living at 31 December 2015 and had a recorded date of incidence with a diagnosis of breast cancer between 2006 and 2015. This time period was chosen to match the specifications of the GBD 2015 study [6]. The list of ICD-10 codes that were used to define mortality due to breast cancer was also used to identify prevalent cases of breast cancer.

Using this method of identifying prevalent cases, we estimated that there were approximately 33,200 individuals in the Scottish population suffering disability due to breast cancer in 2015.

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

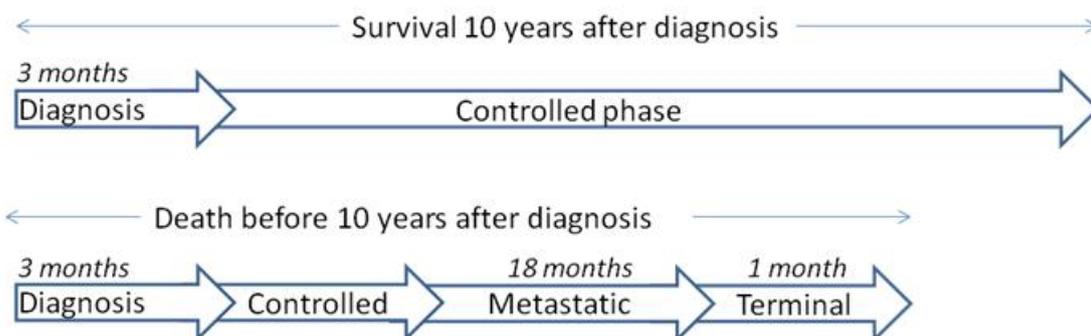
The levels of severity and disability due to breast cancer in Scotland were based on the specifications of the GBD 2015 study [6]. This study allocates cases of breast cancer into four different severity levels: diagnosis and primary therapy, controlled phase, metastatic phase and terminal phase.

The transition from one severity level to another is linked to specific clinical events and mortality outcomes of an individual after their initial incident diagnosis of breast cancer. The amount of days that a breast cancer prevalent case would remain in the diagnosis and primary therapy phase and the

metastatic phase is based on average durations used in the GBD 2015 study (see Figure 2). GBD 2015 defines the severity levels as follows:

“Diagnosis and primary therapy are defined as the time from symptoms onset to end of treatment. Controlled phase is defined as the time after finishing primary treatment and either cure (defined as survival after 10 years) or metastatic phase. Metastatic phase is defined as the time period of intensive treatment for metastatic disease; terminal phase is defined as the one month period prior to death.”

**Figure 2 Transition from one severity level to another for a cancer case. Individuals dying before ten years after diagnosis will go through all the cancer stages and, except for the controlled stage, remain in it for a fixed period of time. The duration at each stage is based on the results from GBD 2015 study [6]**



The disability weights were developed by the GBD study through surveys of the general public and take into account the consequences of each disease and injury [9]. The severity distribution and disability weights for breast cancer, as well as the YLD for each severity level are outlined in Table 1.

Once the disability weight of each severity level was taken into account, individuals were estimated to be suffering approximately 2,400 YLD in 2015 due to living with breast cancer.

The GBD study proposes a fifth level of severity for breast cancer that considers the life-long consequences of a mastectomy. The disability weight of this fifth severity level is lower than the disability weight of the controlled phase. After consulting with our disease experts, we decided that this

difference in disability weight was not justifiable and we did not include this severity level in our final estimate. We also estimated DALYs, including this fifth severity level, but it did not make a noticeable change to the final burden. The reduction in disability weight is compensated for by the fact that individuals undergoing a mastectomy remain in that fifth severity level for life, instead of the fixed ten years we assumed for the controlled phase.

**Table 1 Severity levels, description and disability weights associated with breast cancer in 2015.**

Severity level	Description	Individuals	Disability weight
Diagnosis and primary therapy	Has pain, nausea, fatigue, weight loss and high anxiety.	1,001	0.288
Controlled phase	Has a chronic disease that requires medication every day and causes some worry but minimal interference with daily activities.	30,417	0.049
Metastatic phase	Has severe pain, extreme fatigue, weight loss and high anxiety.	1,609	0.451
Terminal phase	Has lost a lot of weight and regularly uses strong medication to avoid constant pain. The person has no appetite, feels nauseous, and needs to spend most of the day in bed.	129	0.540

## Data quality

In order to provide a measure of the degree of accuracy<sup>2</sup> and relevance<sup>3</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>2</sup> How precise, unbiased or certain the estimate is.

<sup>3</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 breast cancer in Scotland are green,  **highly accurate and relevant.**

The publication Cancer in Scotland [8] estimates a prevalence rate for survivors up to 10 years for this type of cancer of 1,207 per 100,000, for the year 2015. This is equivalent to 33,300 prevalent cases. Our estimate of 33,200 cases is slightly lower because the SBoD methodology considers partial years, that is an individual being diagnosed at some point in 2015 contributes to the prevalence count as a fraction, to represent the remaining year. Additionally, the breast cancer burden in Scotland is mostly caused by fatal outcomes, which are very well recorded in the register of deaths [2], hence we believe that these are highly accurate and relevant.

## **What next to improve estimates for breast cancer**

Future work on the SBoD study will attempt to refine the definition of the transitions from one severity level to another. This work will use more detailed information from the Cancer Registry [9] to determine the amount of time an individual spends in each of the four phases and take into account diseases stage at diagnosis, instead of relying on average durations. For instance, prevalent cases detected very early (for instance, through a cancer screening program) may have a different disease and disability trajectory from other cancers.

Further work will also be done to improve the redistribution of ill-defined deaths, taking into account both the underlying and the contributory cause to classify the death.

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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