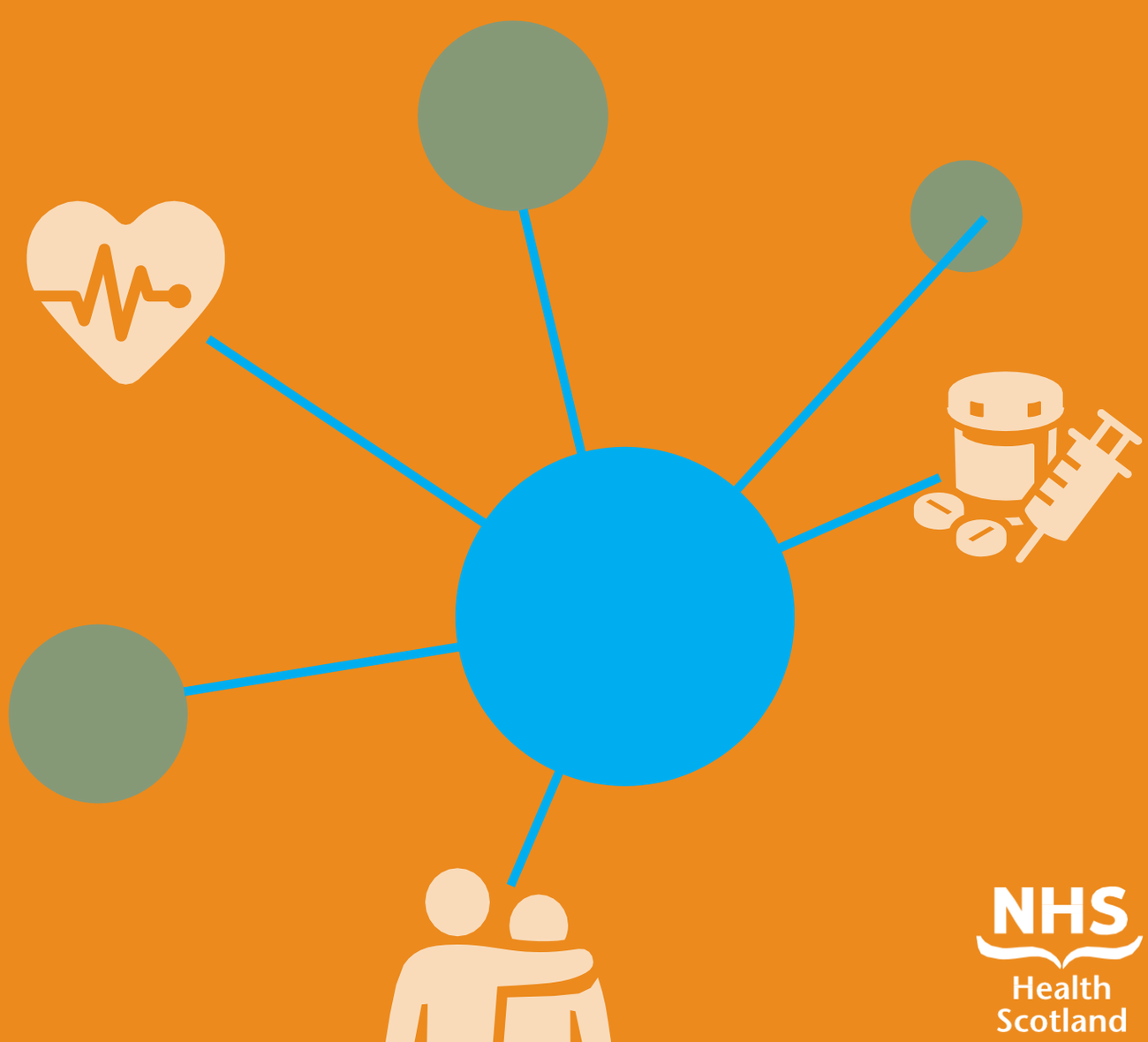
ScotPHO
Public Health Information for Scotland

The Scottish Burden of Disease Study, 2016

Colorectal 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 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 colon and rectum cancer (CRC) in SBoD.

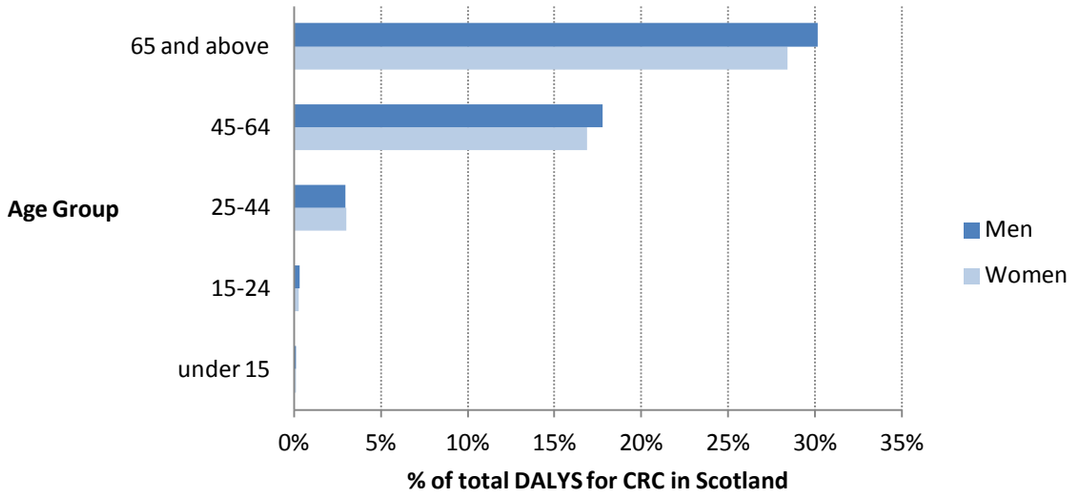
Burden of disease studies aim to estimate the difference between ideal and actual health in a country or region at a specific point in time. Individuals can suffer non-fatal health loss due to suffering disability attributable to a disease or injury, or suffer fatal health loss which is early death due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

CRC was the 15th most common cause of disease burden in Scotland in 2016, resulting in a total of approximately 25,000 DALYs. Of this total burden, 86% was due to premature mortality attributed to CRC and 14% was attributed to the health loss suffered due to living with CRC.

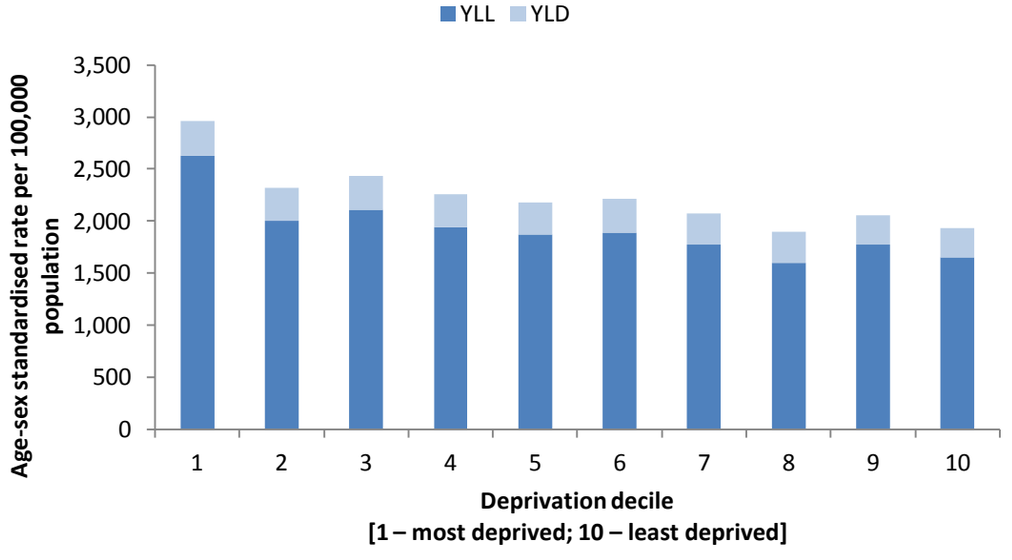
Figure 1 Percentage of total DALYs by gender and age-group for CRC



Men contributed slightly more to the burden than women (53% and 47% respectively). Overall 58% of the total CRC burden was contributed by individuals aged 65 years and over, as outlined in Figure 1. Note that the burden which we are describing is the absolute burden and has not been adjusted for the age/gender case-mix.

The age standardised DALY rates for CRC, by deprivation[1] decile, are shown in Figure 2. Individuals in the most deprived decile experienced a burden that was 1.3 times greater than individuals in the least deprived decile.

Figure 2 CRC DALY (rates per 100,000[2]) 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 colon and rectum 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 CRC 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 1,732 deaths per year caused by CRC. 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 2016 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 CRC mortality count 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. 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 CRC, approximately 6% of the mortality count comes from these ill-defined deaths. For this reason, the number of deaths due to CRC 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 2014-2016 gender-specific National Life Tables for Scotland [6]. There were approximately 22,000 YLL due to CRC in Scotland in 2016. Dividing the total YLL for CRC by the total number of deaths indicates that, on average, individuals who die due to CRC, die 12.5 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 colon and rectum 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 CRC in 2016 we used individual level data from the Scottish Cancer Registry and linked it to the NRS Register of Deaths using the individual Community Health Index (CHI). The linkage of datasets allowed us to identify individuals that were still living at 31 December 2016 and had a recorded date of incidence with a diagnosis of CRC between 2006 and 2016. This time period was chosen to match the specifications of the GBD 2016 study [7]. The list of ICD-10 codes that were used to define mortality due to CRC was also used to identify prevalent cases of CRC.

Using this method of identifying prevalent cases, we estimated that there were approximately 25,600 individuals in the Scottish population suffering disability due to CRC in 2016.

Severity distribution and disability weights

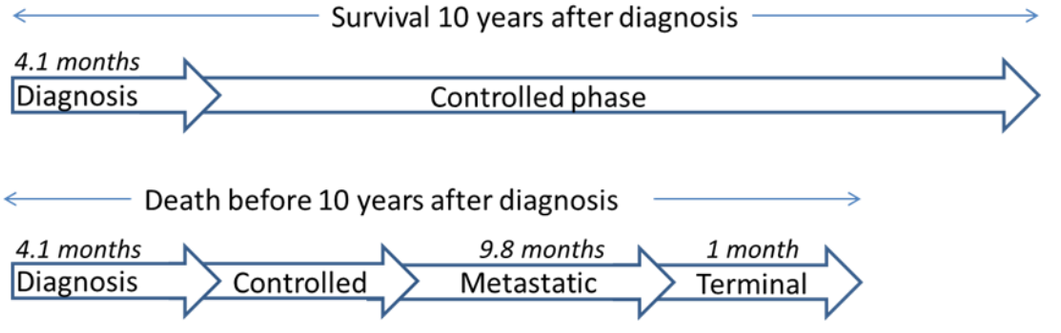
The levels of severity and disability due to CRC in Scotland were based on the specifications of the GBD 2016 study [8]. This study allocates cases of CRC into four different severity levels: diagnosis and primary therapy, controlled phase, metastatic phase and terminal phase.

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 CRC. The amount of days that a CRC 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 [9]

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 [10]. The severity distribution and disability weights for CRC, as well as the YLD for each severity level are outlined in Table 1.

Table 1 Description Severity levels, description and disability weights associated with TBLC in 2016.

Severity level	Description	Individuals	Disability weight
Diagnosis and primary therapy	Has pain, nausea, fatigue, weight loss and high anxiety.	682	0.288
Controlled phase	Has a chronic disease that requires medication every day and causes some worry but minimal interference with daily activities.	23,584	0.049
Metastatic phase	Has severe pain, extreme fatigue, weight loss and high anxiety.	1,305	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.	174	0.540

In addition, we also consider the burden associated with the long-life consequences of a colectomy and ileostomy, for those individuals that survive longer than ten years and underwent this procedure as part of the cancer treatment.

Once the disability weight of each severity level was taken into account, individuals were estimated to be suffering approximately 1,000 YLD in 2015 due to living with CRC.

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.

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

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 TBLC 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 398.4 and 311.8 per 100 000 for men and women respectively. This is equivalent to 19,000 prevalent cases. Our estimate of approximately 26,000 prevalent cases also includes the ICD-10 code C21 (malignant neoplasm of anus and anal canal), and survivors of cancer beyond ten years who are living with the consequences of a stoma.

Additionally, the burden of CRC 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 colon and rectum 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) 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 August 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 August 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 August 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] Supplement to: 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.

[8] 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.

[9] Vos T, Allen C, Arora M, Barber RM, Bhutta ZA, Brown A, et al. Global, regional, and national incidence, prevalence, and years lived with disability for 310 diseases and injuries, 1990-2015: a systematic analysis for the Global Burden of Disease Study 2015. The Lancet 2016;388(10053):1545-602.

[10] 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.

[8] ISD Scotland. Cancer in Scotland. NHS National Services Scotland, Available from: URL: http://www.isdscotland.org/Health-Topics/Cancer/Publications/2017-04-25/Cancer_in_Scotland_summary_m.pdf (Accessed 03 July 2017).

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