

Public Health Scotland: Scottish Burden of Disease Study

July 2023

Cancer metadata

1. Background

The Scottish Burden of Disease (SBOD) is an ongoing study conducted by Public Health Scotland [1]. The study has been designed to show the extent to which different causes of diseases and injury affect Scotland's health and life expectancy. To do this, the study has adopted and implemented an internationally recognised approach, referred to as 'Burden of Disease'.

Table 1. SBOD cancer metadata summary

Metadata indicator	Description
Description	Scottish Burden of Disease estimates of burden due to cancers
Data definitions and methodology	See description below for full details of definitions and methodology
Data source(s)	Scottish Morbidity Records: General Acute Inpatient and Day Case (SMR01) Scottish Cancer Registry (SMR06) National Records of Scotland Vital Events (deaths)
Baseline and comparability over time	Baseline year 2019; future data points will be comparable with baseline.
Robustness and data limitations	In order to provide a measure of accuracy and relevance 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. Estimates of cancer burden are deemed to be Green: highly accurate and relevant.
Data availability	Subject to statistical disclosure control, data is available at sex and 5-year age bands and at national, health board and local authority level.

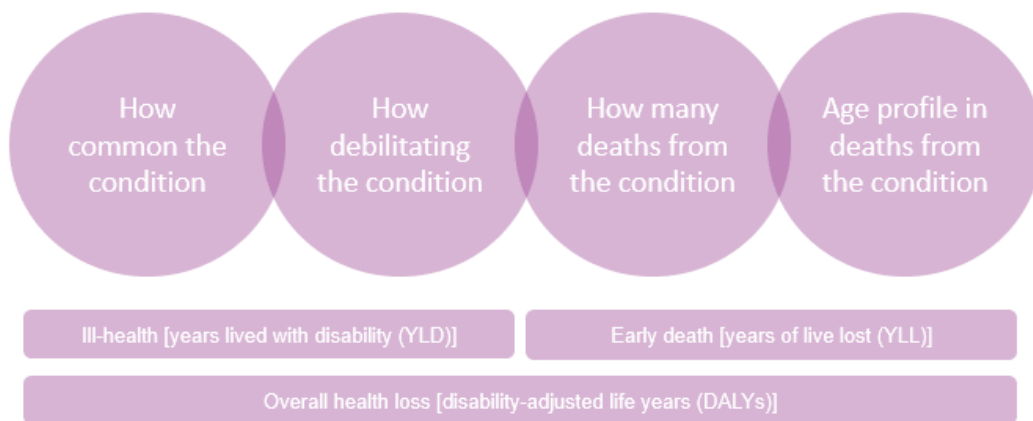
2. Methodology and data definitions

Study permissions

All individual-level data extraction, linkage and manipulation presented in the SBOD study was carried out by study team members at ISD Scotland. Permission to link previously unlinked datasets was approved following an application to the Privacy Advisory Committee (PAC) under the reference 54/14. Approval was granted on 23 March 2018 for a period of 5 years. All SBOD study team members have completed and maintained up-to-date Information Governance training in handling electronic health records.

2.1 Summary of burden of disease methodology

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)



2.2 Cancer classification in Scottish Burden of Disease Study

In burden of disease studies, causes of disease, injury and mortality are classified using the International Classification of Diseases version 10 (ICD), with a hierarchical tree structure used to allocate causes of disease, injury and mortality into different levels of the grouping. This classification is commonly referred to as the cause list. The cause list used in the Global Burden of Disease (GBD) 2016 study has largely been implemented in the SBOD study, with some minor changes [1]

Overall, 29 cancer sub types are included in the Scottish Burden of Disease study (see Table 1). The ICD-10 codes used to identify these cancer types are available upon request from SBOD study team.

Table 2. Cancers included in Scottish Burden of Disease Study

Cancer	Cancer sub type
Lip and oral cavity cancer	
Nasopharynx cancer	
Other pharynx cancer	
Oesophageal cancer	
Stomach cancer	
Colon and rectum cancer	Colon and rectum cancers
	Stoma due to colon and rectum cancer
Liver cancer	
Gallbladder and biliary tract cancer	
Pancreatic cancer	
Larynx cancer	Larynx cancer
	Laryngectomy due to larynx cancer
Tracheal, bronchus, and lung cancer	
Malignant skin melanoma	
Non-melanoma skin cancer	
Breast cancer	Breast cancer
	Mastectomy due to breast cancer
Cervical cancer	
Uterine cancer	
Ovarian cancer	
Prostate cancer	Prostate cancer
	Impotence and incontinence due to prostate cancer
Testicular cancer	
Kidney cancer	
Bladder cancer	Bladder cancer
	Urinary incontinence due to bladder cancer
Brain and nervous system cancer	
Thyroid cancer	
Mesothelioma	
Hodgkin lymphoma	
Non-Hodgkin's lymphoma	
Multiple myeloma	
Leukaemia	Leukaemia - L4
	Acute lymphoid leukemia ALL
	Acute myeloid leukemia AML
	Chronic lymphoid leukemia CLL
	Chronic myeloid leukemia CML
	Other leukaemia
Other neoplasms	

2.4 Years Lived with Disability (YLD)

Years lived with disability (YLD) are estimated using:

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

Estimating the number of individuals suffering ill-health from cancer

To estimate prevalent cases of each cancer type, 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 2019 and had a recorded date of incidence with a diagnosis of cancer between 2006 and 2019. This time period was chosen to match the specifications of the GBD2016 study [1]. The list of ICD-10 codes that were used to define mortality due to each type of cancer was also used to identify prevalent cancer cases.

Severity distributions

As part of the SBOD2016 study, national and sub-national severity distributions were derived for 21 cancer types using individual patient records from the Scottish Cancer Registry, which holds registration records from 1980 onwards of all incident cancers diagnosed within the NHS in Scotland [3].

Cancer types were restricted to those that had four common sequelae: (i) diagnosis and primary therapy phase; (ii) controlled phase; (iii) metastatic phase; and (iv) terminal phase. This approach was chosen to avoid attribution of differences due to interpretation of the GBD 2016 model when dealing with additional specific sequelae, such as procedural [1]. For example, the GBD 2016 breast cancer model has an additional mastectomy sequelae which includes details of International Classification of Diseases, Ninth Revision, Clinical Modification (ICD-9-CM) codes used to define the procedure. However, in Scotland procedural codes are defined using Office of Population Censuses and Surveys Classification of Interventions and Procedures version 4 (OPCS-4) codes. Other cancers excluded on this basis include: Bladder; Breast; Colorectal; Larynx; Leukaemia; Non-melanoma skin cancer; Prostate and other neoplasms. For these cancers, severity distributions were based on the specifications of the GBD2016 study.

For the remaining cancers, the disease model used to define the sequelae of each case was developed using definitions from the GBD 2016 technical appendix [REF]. We calculated 10-year prevalence of the incidence cohort for 21 cancer types to establish prevalent cases. Prevalent cases were then apportioned to each sequelae using fixed durations found in the GBD 2016 technical appendix for the diagnosis and primary therapy phase, metastatic phase and terminal phase (See Table 2). Cases were assigned to the controlled phase if they did not satisfy the time-based criteria of the other three sequelae.

Patients were followed up over time and the date and cause of death were obtained from the National Records of Scotland's register of deaths. Using deterministic matching of a patient-identifier between the cancer registry and register of death, we could confidently classify and exclude cases in accordance with the GBD fixed duration cancer survival model definitions for each

cancer type. The operationalisation of the allocation to individual phases was carried out by converting the GBD 2016 fixed durations to days, and applying from the date of the incident registration on the Scottish Cancer Registry. The availability of specific death dates meant that the time to death from incident registration could be calculated in days for both exclusion and classification purposes. Due to the ability to link patient records and the nature of the registrations on Scottish Cancer Registry, we did not require persistent identification of ICD-10 codes during the follow-up period.

Disability weights

Disability weights, which represent the magnitude of health loss associated with specific health outcomes, are used to calculate years lived with disability (YLD) for these outcomes in a given population. The weights are measured on a scale from 0 to 1, where 0 equals a state of full health and 1 equals death. Disability weights for each of the four sequelae of cancer were derived from the GBD 2016 study (Table 3) [1].

Table 3. Disability weights assigned to each cancer sequelae

Phase/sequelae	Unadjusted Disability Weight
Diagnosis and primary therapy phase	0.288
Controlled phase	0.049
Metastatic phase	0.451
Terminal phase	0.540

Further information on this method is available from Wyper GMA, Grant I, Fletcher E, McCartney G, Stockton DL. The impact of worldwide, national and sub-national severity distributions in Burden of Disease studies: A case study of cancers in Scotland. PLoS One. 2019 Aug 9;14(8):e0221026. doi: 10.1371/journal.pone.0221026

Table 3. Survival durations assigned to each sequelae by cancer type

Cancer type	Phase/sequelae duration in months			
	Diagnosis and primary therapy phase	Controlled phase	Metastatic phase	Terminal phase
Bladder	5.10		5.80	
Brain and nervous system	5.00		6.93	
Breast	3.00		17.7	
Cervical	4.80		9.21	
Colon and rectum	4.00		9.69	
Gallbladder and biliary tract	4.00		3.47	
Hodgkin lymphoma	3.70		26.00	
Kidney	5.30		5.38	
Larynx	5.30		8.84	
Lip and oral cavity	5.30		9.33	
Liver	4.00		2.51	
Lymphoid leukaemia – Acute/Chronic	12.00/6.00		7.02/4.60	
Malignant skin melanoma	2.90		7.18	
Mesothelioma	4.00		7.75	
Multiple myeloma	7.00	Remainder of time after classifying other sequelae	36.82	One month
Myeloid leukaemia	6.00		4.60	
Nasopharynx	5.30		13.19	
Non-Hodgkin's lymphoma	3.70		7.70	
Other neoplasms	4.40		15.81	
Oesophageal	5.00		4.60	
Other pharynx	5.30		7.91	
Other leukaemia	6.00		48.00	
Ovarian	3.20		25.60	
Pancreatic	4.10		2.54	
Prostate	4.00		30.35	
Stomach	5.20		3.88	
Testicular	3.70		19.47	
Thyroid	3.00		19.39	
Tracheal, bronchus, and lung	3.30		4.51	
Uterine	4.60		11.60	

References

1. 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* [Internet]. 2017;390(10100):1211–1259. pmid:28919117
2. Information Services Division Scotland [Internet]. Scottish Cancer Registry [cited 2019 Apr 30]. <https://www.isdscotland.org/Health-Topics/Cancer/Scottish-Cancer-Registry/> [Ref list]
- 3 Wyper GMA, Grant I, Fletcher E, McCartney G, Stockton DL. The impact of worldwide, national and sub-national severity distributions in Burden of Disease studies: A case study of cancers in Scotland. *PLoS One*. 2019 Aug 9;14(8):e0221026. doi: 10.1371/journal.pone.0221026. PMID: 31398232; PMCID: PMC6688784.