
Register-based trace back of cancer on death certificates: An approach to estimating death certificate initiated cancer cases, 2005–2022

The Swedish National Cancer Register was established in 1958 and contains data on diagnosed primary tumours. The register is of both high quality and high completeness. However, the completeness tends to be lower for advanced, late stage tumours diagnosed with a poor prognosis, especially among older patients. In other national cancer registers, a non-negligible proportion of these tumours are identified through follow-up of cancer diagnoses recorded on death certificates. In this report, a register-based method for estimating death certificate initiated cancer cases is described, utilising data from the National Cause of Death Register and the National Patient Register to supplement the Cancer Register. This method aims at estimating the number of cancer cases that could potentially be identified through a systematic follow-up of cancer noted on death certificates.

Registration in the Cancer Register

The Swedish National Cancer Register (Swedish abbreviation: CAN) contains data on all malignant tumours, as well as certain benign tumours and tumour-like conditions. The main purpose of the register is to monitor cancer incidence and cancer survival over time and to provide a national infrastructure for research and follow-up in the field of cancer. According to Swedish legislation, all healthcare providers are mandated to report newly diagnosed tumours and tumour-like conditions to the Cancer Register. A recurrence is not recorded, as it is not a new primary tumour, and metastases are only recorded when the primary tumour is unknown. Both clinical health care facilities and pathology departments involved in cancer diagnostics are obliged to report to the Cancer Register (HSLF-FS 2016:7). Independent reporting of a) clinical assessment and b) pathology report is required for a cancer report to be considered complete and included in the register (exceptions may occur, however, see also changes in regulations according to HSLF-FS 2023:36). Clinical diagnoses are reported either on separate forms (electronic forms were introduced in 2018) or by registration in quality registers, while pathological reports are conveyed through automatic transfer from the laboratories' record systems. In a first step, cancer

notifications are reviewed at Regional Cancer Centres (RCC) to determine whether the notification should generate a new tumour registration or if information concerning an existing tumour in the register should be updated. CAN is updated annually with new incident cases, including unreported cases from previous calendar years. Cases with altered diagnosis since the time of initial registration are simultaneously updated.

Non-notified cancer cases and trace back of cancer noted on death certificates

Underreporting of cancer cases in CAN is comparatively high for tumours diagnosed at a late stage and with a poor prognosis, especially among older patients (1, 3). This primarily reflects a consequence of clinical practice where invasive sampling on an x-ray-confirmed internal tumour is refrained from when the procedure is unlikely to affect treatment or provide any benefit to the patient. Consequently, there is no notification from the pathology laboratory, which decreases the likelihood that the cancer case will be recorded in CAN. Furthermore, few clinical autopsies are performed in Sweden today, which could otherwise have generated a cancer notification. In the cancer registries of most other countries, including the other Nordic countries, systems have been established for systematic follow-up of cancer-related deaths to confirm diagnosis, date of diagnosis and other information in order to be able to include the case in the register (2). However, a similar system has never been introduced in Sweden and therefore there is currently no routine follow-up of cancer listed as a cause of death on death certificates. The introduction of such a system would probably require a change in the legislation.

Terminology

Death certificate notification (DCN): Not part of the Swedish system, but internationally means that cancer stated as a cause of death initiates a follow-up.

Death certificate initiated cases (DCI): A DCN, which after follow-up in medical records or similar, is considered confirmed.

Death certificate only (DCO): A DCN where follow-up has not been carried out or where, after follow-up, it has not been possible to confirm or disprove cancer.

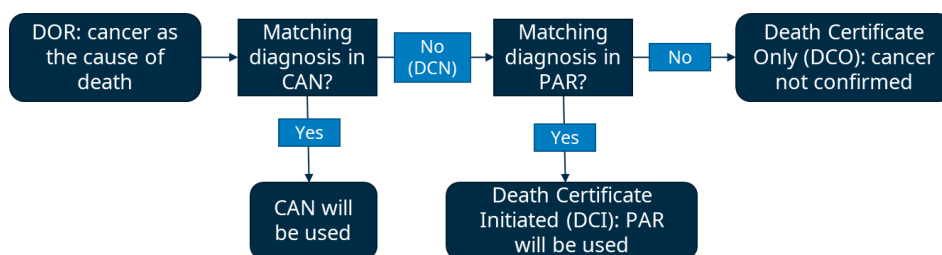
Findings in a previous study from The National Board of Health and Welfare and RCC indicate that Cancer Register data supplemented with information from the Cause of Death Register and the Patient Register provide a good approximation of cancer cases that in other countries would

have been identified through death certificate notifications (3). The study was limited to pancreatic and lung cancer diagnosed in 2013.

Register-based trace back of cancer noted on death certificates

Below, a method is described for register-based trace back of cancer noted on death certificates, and further, how its application could affect the annual cancer incidence estimation for various forms of cancer. The idea of the method is that cancer registered as a cause of death in the Cause of Death Register (Swedish abbreviation: DORS), but not in the Cancer Register (CAN), is to be considered a confirmed cancer case if the cancer at some point has also been registered in the Patient Register (Swedish abbreviation: PAR). The non-notified cancer cases identified and confirmed in this way are considered "Death Certificate Initiated" cases. Figure 1 shows the method schematically.

Figure 1. Method for identifying *Death Certificate Initiated* cancer cases



In a first step, information in DORS is used to identify deaths where cancer has been noted as a cause of death. In the next step, each cancer-related cause of death is compared against CAN to see if a matching cancer diagnosis was registered before the death. If a matching diagnosis cannot be identified in CAN, the cause of death is considered a "Death Certificate Notification" (DCN). For each DCN, a matching diagnosis preceding the death is sought in PAR (outpatient or inpatient care). A matching diagnosis is considered to confirm the cancer case (Death Certificate Initiated cancer, DCI), otherwise the cause of death is considered an unconfirmed case (Death Certificate Only, DCO). Thus, by using this method, confirmed cancer cases that were not reported to the Cancer Register, DCIs, are identified. In this report, DCIs represent an estimation of non-reported cancer cases and are presented as numbers, as well as percentages of cases already registered in CAN.

Method

Deaths with a diagnosis code related to cancer, as an underlying or contributing cause of death and with complete dates of death between 2005

and 2022, were identified. Cancer registrations in DORS with diagnosis code C77–C79 (secondary malignant tumours (metastases)) were excluded if the person also had a primary tumour registered. This was done in order to mimic, as closely as possible, registration in the cancer register where metastases are not included. Starting from 1997, matching diagnoses (as outlined in Table 1) were searched for in CAN, and if no match was found, in PAR. The purpose of the grouping of diagnosis codes in Table 1 was to identify matching cancer cases between DORS, CAN and PAR, and a match did not necessarily require the same diagnosis code. For example, a tumour of unspecified site identified as a cause of death was considered to match a broad group of diagnoses in both CAN and PAR. What should be considered an appropriate matching diagnosis depends on the research question at hand.

Table 1. Matching diagnoses in the Cause of Death Register, the Cancer Register and the Patient Register

A cause of death within the group specified in column "DORS (ICD-10)" was considered to match diagnoses in "CAN (ICD-O/2)" and in "PAR (ICD-10-SE)"

Group	DORS (ICD-10)	CAN (ICD-O/2)	PAR (ICD-10-SE)
Head, neck	C00–C14, C30–C32, C39.0, C39.9	C00–C14, C30–C32, C39.0, C39.9, C76.0, C77.0, C80.9	C00–C14, C30–C32, C39.0, C39.9, C76.0
Thorax	C33–C38, C39.8–C39.9, C45	C33–C38, C39.8–C39.9, C45, C76.1, C77.1, C80.9	C33–C38, C39.8–C39.9, C45, C76.1
Bone and articular cartilage	C40–C41	C40–C41, C76.4–C76.5	C40–C41, C76.4–C76.5
Skin, other connective and soft tissue	C43–C44, C46, C49	C43–C44, C49	C43–C44, C46, C49
Digestive organs	C15–C26, C48	C15–C26, C48, C76.2, C80.9	C15–C26, C48, C76.2
Breast	C50	C50	C50
Vulva	C51, C43–C44	C51, C43–C44	C51, C43–C44
Female genital organs	C52–C58, C48	C51–C58, C451, C48, C76.2–C76.3	C51–C58, C4-8, C76.2–C76.3
Penis	C60, C43–C44, C63.9	C60, C43–C44, C63.9	C60, C43–C44, C63.9
Prostate	C61	C61	C61

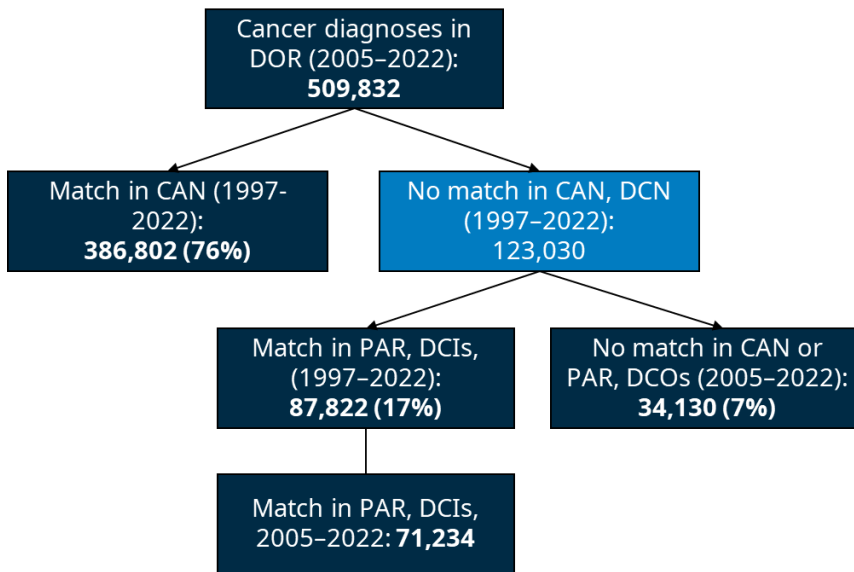
Group	DORS (ICD-10)	CAN (ICD-O/2)	PAR (ICD-10-SE)
Testis and other and unspecified male genital organs	C62, C630–C63.7, C63.9	C62, C63.0–C63.7, C63.9	C62, C63.0–C63.7, C63.9
Kidney and renal pelvis	C64–C65, C68.8–C68.9	C64–C65, C68.8–C68.9	C64–C65, C68.8–C68.9
Ureter, bladder and urethra	C66–C68.9	C66–C68.9	C66–C68.9
Eye, brain and other parts of central nervous system	C69, C70–C72, D32–D33, D43	C69, C70–C72, C751–C75.3	C69, C70–C72, C751–C75.3, D32–D33, D43
Peripheral nerves and autonomic nervous system	C47	C47	C47
Thyroid gland and endocrine glands	C73–C75, D35, D44.3–D44.5	C73–C75	C73–C75, D35, D44.3–D44.5
Haematological malignancies	C81–C96, D45.0–D47.9	C81–C96, D45.0–D47.9	C81–C96, D45.0–D47.9
Ill-defined, other secondary and unspecified sites, secondary malignancies	C76–C80	C00–C43, C45–C80	C00–C43, C45–C80

Cancer noted on the death certificate with a match in CAN was considered to have a diagnosis code according to ICD-O/2, a match in PAR (DCI) according to the ICD-10-SE code, and deaths without a match (DCO) according to the ICD-10 code in DORS. It is not uncommon with several matching diagnoses/healthcare visits in PAR for each cause of death. For DCIs, the first date of visit for the most recent matching tumour diagnosis was selected in order to mimic the date of diagnosis in CAN.

Non-reported cancer cases have decreased over time

In DORS, 509,832 cancer-related causes of death were identified, of which 76 percent were matched to a diagnosis in CAN and 17 percent to a diagnosis in PAR. The remaining 7 percent were classified as DCOs (Figure 2).

Figure 2. Flow chart

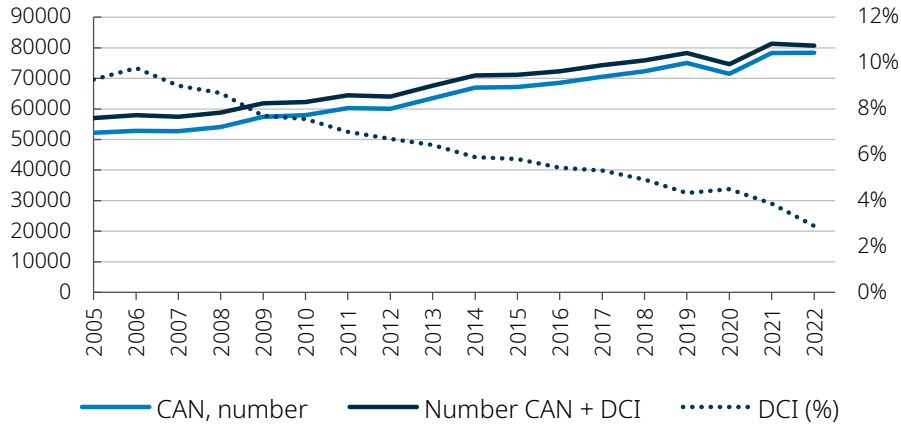


Source: The National Cancer Register, the National Cause of Death Register and the National Patient Register, the National Board of Health and Welfare

During the study period, a yearly average of 3,958 cancer cases were identified as DCIs. If these non-notified cases were to be added to CAN, it would correspond to an increase of 6.4 percent. During the latter part of the study period (2014–2022), the corresponding estimate was 4.8 percent, which is 3.2 percentage points lower compared with the first part of the study period (8.0 percent 2005–2013). In terms of age at diagnosis, the proportion of DCIs was higher among individuals 80 years or older at diagnosis, 12.3 percent during the period 2014–2022, compared with 2.7 percent in individuals younger than 80 years (Table 1B in the Excel appendix). DCIs have continuously decreased over time, indicating that the completeness of the Cancer Register has improved (Figure 3). However, this needs to be interpreted with some caution since the method is affected by a time lag primarily affecting the last years of the series for DCI-identified cancer. The lag is partly caused by a general delay in reporting to the Cancer Register, but mainly by that time needs to pass between the detection of cancer and the occurrence of death.

Figure 3. Number of reported cancer cases and DCIs, and DCIs as a percentage (%) of reported cancer cases, 2005–2022

Number of reported cancer cases and DCIs per year of diagnosis (left axis), DCIs as a percentage of cases in the Cancer Register (right axis)

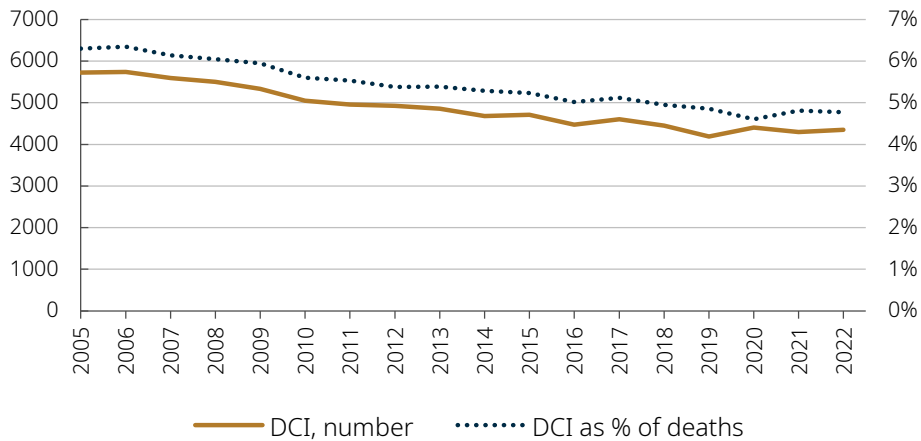


Source: The National Cancer Register, the National Cause of Death Register and the National Patient Register, the National Board of Health and Welfare

A potentially improved completeness is, however, also observed when DCIs are presented by year of death instead of year of diagnosis, which indicates that the improvement does not simply reflect a lag. Figure 4 shows DCIs by numbers and as percentage of all deaths (regardless of cause) per year (Figures by age group are presented in the Excel appendix, Table 2B). The trend is also declining, but is less pronounced and without the distinct decline in recent years. The trend towards fewer non-reported cases coincides with the period when national cancer quality registries were introduced for almost all forms of cancer. It is likely that it has improved reporting and, to a large extent, compensated for a reduced reporting from clinical autopsies, which has decreased in numbers since the 1980s.

Figure 4. Number of DCIs per year of death and as a percentage (%) of all deaths

Number of DCIs (left axis), DCIs as a percentage of all deaths (right axis)



Source: The National Cancer Register, the National Cause of Death Register and the National Patient Register, the National Board of Health and Welfare

Non-reporting varies by cancer form

Generally, underreporting of cancer diagnoses tends to be higher for older patients, for tumours with an internal localisation and with a short survival expectancy. The highest proportion of DCI was identified for malignant tumours in the respiratory organs and organs of the chest cavity (11.9 percent), in bones and joint cartilage (13.8 percent), in the digestive organs (12 percent), in mesothelial tissue and soft tissue (23.2 percent) as well as in the eye, brain and other parts of the central nervous system (10.6 percent) (Table 2).

Table 2. DCIs and DCOs as number and percentage (%) of all reported cancer cases, per diagnosis group, 2005–2022

Diagnosis group	CAN, number	DCIs, number	DCIs (%) *	DCOs, number	DCOs (%) *
Tumours in the mammary gland	164,411	2,101	1,3%	2,870	1,7%
Tumours of the respiratory and chest cavity organs	81,811	9,766	11,9%	4,974	6,1%
Tumours of bone and articular cartilage	1,507	208	13,8%	278	18,4%
Tumours of the female genital organs	53,763	1,551	2,9%	2,037	3,8%
Tumours of the male genital organs	191,478	5,973	3,1%	2,256	1,2%
Tumours of lymphatic, hematopoietic and related tissues	76,468	4,505	5,9%	1,539	2,0%
Tumours of the lip, oral cavity and pharynx	20,787	281	1,4%	218	1,0%
Tumours of the digestive organs	196,854	23,584	12,0%	9,239	4,7%
Tumours of mesothelial (body cavity covering) tissue and soft tissue	7,335	1,703	23,2%	703	9,6%
Tumours of the thyroid and other endocrine glands	29,535	474	1,6%	391	1,3%
Tumours of the urinary tract	77,147	4,923	6,4%	2,128	2,8%

Diagnosis group	CAN, number	DCIs, number	DCIs (%) *	DCOs, number	DCOs (%) *
Tumours of the eye, brain and other parts of the central nervous system	29,254	3,088	10,6%	604	2,1%
Tumours with incompletely defined, secondary and unspecified locations	20,180	6,216	30,8%	4,558	22,6%
Melanoma and other tumours of the skin	193,205	2,656	1,4%	988	0,5%
Tumours of uncertain or unknown nature	16,004	4,205	26,3%	1,347	8,4%

* DCI and DCO as a percentage of all reported cancer cases in each diagnosis group. Source: The National Cancer Register, the National Cause of Death Register and the National Patient Register, the National Board of Health and Welfare

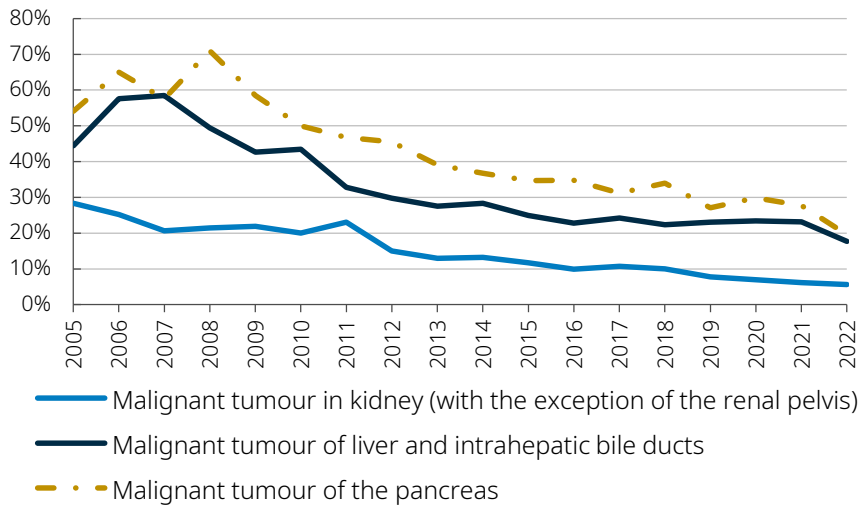
Following stratification into two age groups, individuals older or younger than 80 years at the time of diagnosis, marked differences could be observed for different forms of cancer. Particularly large differences were found for tumours in the eye and brain, where the DCIs were 83.2 percent in the older age group, compared with 5.1 percent in the younger age group. Marked differences could also be observed for tumours in bones and articular cartilage (55.2 percent compared to 10.4 percent), in the respiratory and chest cavity organs (30.1 percent compared to 8 percent) and in the digestive organs (26.1 percent compared to 7.3 percent). See table 3B in the Excel appendix.

Decrease in non-reporting of common forms of cancer

Figure 5A–D shows DCIs (as percentages) for 12 common forms of cancers (note that the figures have different scales on the y-axis). The DCIs have decreased over time for all cancer forms presented below. The largest absolute reduction was observed for cancers of the pancreas and liver, both with a high percentage of DCIs in the beginning of the period. The largest percentage reduction was seen for prostate and breast cancer, as well as for lymphocytic leukaemia and myeloma. The DCIs, however, remains high for both liver and pancreatic cancer, with five-year (2018–2022) average values of 22 and 28 percent, respectively, as well as for lung and brain cancer with estimates of around 10 percent. Corresponding estimates for cancers with a generally low proportion of DCIs — breast, prostate, bladder and rectum — were 0.4–1.9 percent (Table 6A–L in the Excel appendix).

Figure 5A. Kidney, liver and pancreatic cancer, 2005–2022

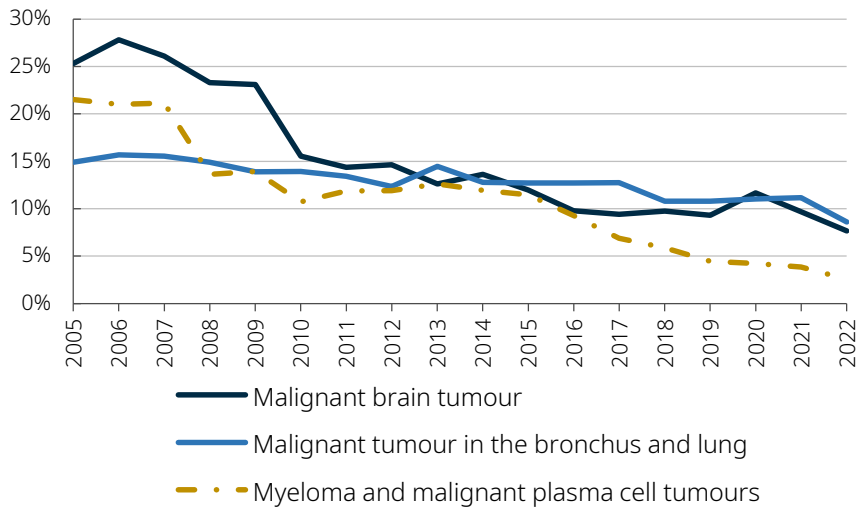
DCIs as percentage (%) of cancer cases registered in the Cancer Register



Source: The National Cancer Register, the National Cause of Death Register and the National Patient Register, the National Board of Health and Welfare

Figure 5B. Brain and lung cancer, and myeloma, 2005–2022

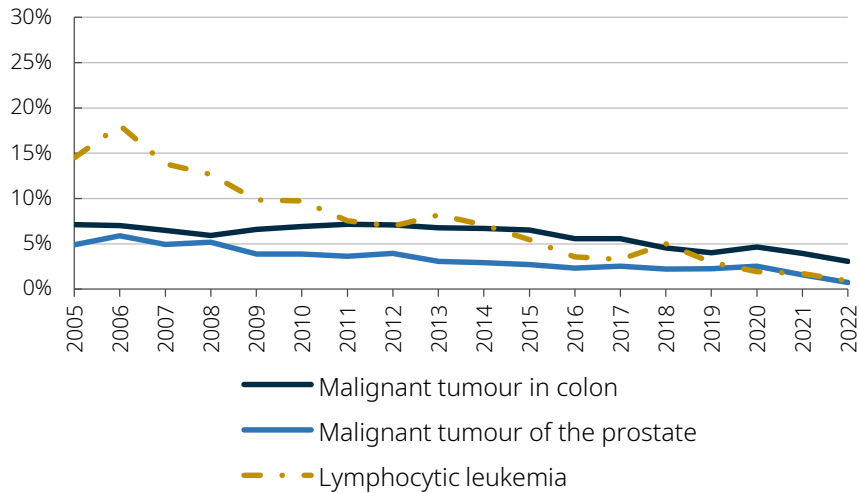
DCIs as percentage (%) of cancer cases registered in the Cancer Register



Source: The National Cancer Register, the National Cause of Death Register and the National Patient Register, the National Board of Health and Welfare

Figure 5C. Colon and prostate cancer, and lymphocytic leukaemia, 2005–2022

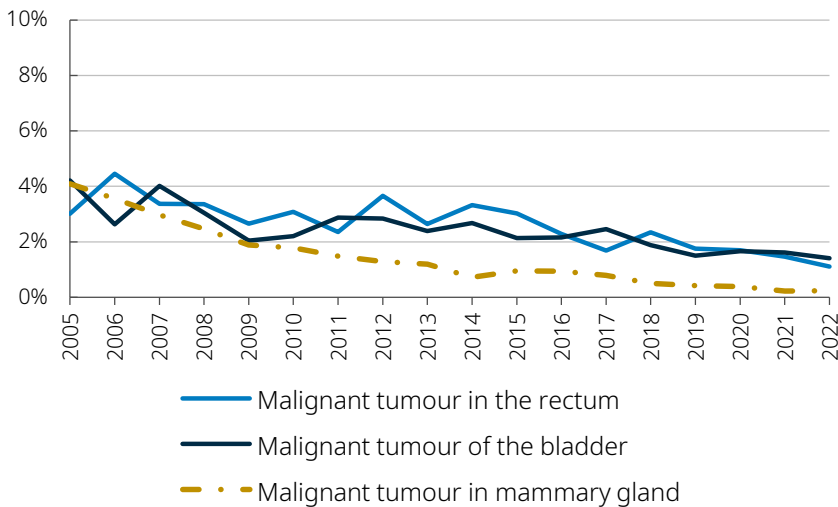
DCIs as percentage (%) of cancer cases registered in the Cancer Register



Source: The National Cancer Register, the National Cause of Death Register and the National Patient Register, the National Board of Health and Welfare

Figure 5D. Rectal, bladder and breast cancer, 2005–2022

DCIs as percentage (%) of cancer cases registered in the Cancer Register



Source: The National Cancer Register, the National Cause of Death Register and the National Patient Register, the National Board of Health and Welfare

Conclusions

The National Cancer Register differs from most other national cancer registers by not having a routine system for follow-up of cancers registered as a cause of death and, if not previously registered, include confirmed cases in the register. The presented results show that a register-based trace back of cancer cases identified in the Cause of Death Register would potentially increase the number of cases in the Cancer Register by an estimated

5 percent. The underreporting was markedly higher among older individuals, as well as for tumours with internal localisation with a poor prognosis. In addition to improving the quality of the cancer register, identification and inclusion of DCIs could facilitate international comparisons and would also be of value for certain research questions.

The Cancer Register is used for a wide range of research- and evaluation purposes, and users should decide on a case-by-case basis whether the method described here, or a variant thereof, is suitable for the question at hand. For specific research questions, the method requires considerations of what is a suitable matching diagnosis in the various registers and at what point in time a cancer should be considered as diagnosed. Cancer cases identified by means of register-based trace back lack information on a number of variables that are included in the cancer register including histopathological diagnosis, basis for the diagnosis, tumour size, lymph node involvement and distant metastases at diagnosis. Tumour cases identified solely through register linkage also lack the rigorous quality control of cancer notifications performed by the RCCs before the data is delivered to the National Board of Health and Welfare.

In this report, we have described a register-based method to identify non-reported cancer cases to the National Cancer Register. Further investigation is needed on how a routine and systematic follow-up of cancer identified on death certificates could be implemented in Sweden. Going forward, we intend to continue developing the register-based method for estimating underreporting and publish updated results on a regular basis.

About the statistics

The statistics have been produced by tracing causes of death related to cancer (ICD codes: C01–C96, D32–D33, D35, D43–D47) on cause of death certificates with complete dates of death between the years 2005 and 2022. Secondary malignant tumours (metastases), C77–C79 were excluded for individuals who also had primary tumours recorded on the death certificate (n = 251,552). Cancer-related causes of death were traced back in CAN, and then in PAR, between the years 1997 and 2022. As it is common to have several matching diagnoses in PAR, the most recent matching diagnosis was utilised, together with the diagnosis date for the first healthcare visit for the specific diagnosis. A total of 1,078 diagnoses identified in DORS, but not matched in CAN or PAR, were excluded from DCOs as they already had representation among the DCIs at the ICD-10 chapter level. Only DCIs with a diagnosis date of 2005 or later are reported in the statistics. The 16,588 causes of death that were matched against diagnoses in PAR between the years 1997 and 2004 are not included in the tables (see Figure 2).

More information

You can find more tables and information here:

<https://www.socialstyrelsen.se/en/statistics-and-data/registers/national-cancer-register/>. If you would like to use our statistical database, please visit:

https://sdb.socialstyrelsen.se/if_can/val_eng.aspx.

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