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Statistical register's production and quality

National Cancer Register

The Swedish National Cancer Register is an incidence-based register containing data on diagnosed primary tumours. The Register contains data on all malignant tumours, as well as certain benign tumours and tumour-like conditions.

Reference period

The Swedish National Cancer Register was established in 1958. The World Health Organization (WHO) has changed the coding instructions for tumour diagnoses on several occasions since the start of the Register, leading to greater precision and granularity. Since 2005, ICD-O/3.2 (*The International Classification of Diseases for Oncology*, version 3.2) has been used. In addition to the current coding instructions, all registered tumours are also coded according to ICD-7 (*International Classification of Diseases*, version 7), which enables long time series. The National Cancer Register is, in part, a living register, and is updated annually with new diagnoses and adjustments with late and changed diagnoses.

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Production of the statistical register

F1 Context of the statistical register

The National Board of Health and Welfare maintains a number of personal ID number-based registers that are used as a basis for statistical and research purposes in health care and social services. The National Cancer Register is a health data register containing information on all tumours or tumour-like conditions diagnosed in Sweden for people registered in Sweden. The purpose of the National Cancer Register is to enable register-based statistics to map the incidence of cancer and changes over time. The data in the Register are used as a basis for Sweden's official statistics on cancer, international statistics on cancer, and prevention and development work in the health care sector. The Register also provides a basis for clinical and epidemiological research as well as enabling international comparisons.

F2 Design

F2.1 Outline of register content

The National Cancer Register contains information on primary tumours diagnosed by health care providers in Sweden. The Register contains data on all malignant tumours, as well as certain benign tumours and tumour-like conditions. Recurrence is not recorded, as it is not a new primary tumour. Metastases are only recorded where the primary tumour is unknown. An individual may have more than one primary tumour and may therefore appear several times in the National Cancer Register. Linked to the National Cancer Register, since 2004, is a register of basal cell carcinoma, a benign tumour that is the most common form of skin cancer.

F2.2 Data sources

The content of the National Cancer Register is based on tumour data reported by hospitals and clinics to six Regional Cancer Centres (RCC) in Sweden, which also coincide with the six hospital regions. RCCs check, classify and compile the cancer notifications, and annually report the previous year's registrations to the National Board of Health and Welfare. Data regarding citizenship, place of registration, immigration and emigration, etc., are taken from the source register RTB (the Total Population Register) provided by Statistics Sweden (SCB). Date of death is taken from Statistics Sweden and the National Cause of Death Register.

F2.3 Time frame

Data on diagnoses of tumours and tumour-like conditions are continuously reported by the healthcare providers making the diagnoses to the RCC. The RCC delivers the previous calendar year's data to the National Board of Health and Welfare by 31 October. The National Cancer Register is produced once per reference year with data on new tumour diagnoses from the previous calendar year, as well as data on late or changed tumour diagnoses, usually shortly after the publication of the annual official statistics. The Register is therefore a living register that is updated annually.

F2.4 Collection procedure

F2.4.1 Data collection methods and providers

When a person is diagnosed with a tumour by a health care provider in Sweden, the details of the tumour are reported to the RCC in the region where they are registered, and coded according to *The International Classification of Diseases for Oncology*, version 3.2 (ICD-O/3.2)¹, which is produced by the WHO. In order to monitor developments over time, information on each tumour is recorded and translated according to previous classifications such as ICD-O/2, ICD-9 and ICD-7 (*International Classification of Diseases*). The National Cancer Register, and the obligation to provide information, is regulated by the Health Data Register Act (1998:543) and associated regulation (2001:709), as well as in the National Board of Health and Welfare's regulation and general advice (HSLF-FS 2016:7) on the obligation to provide information to the National Board of Health and Welfare's National Cancer Register. These regulations sets out the health care provider's obligation to report data on tumours and tumour-like conditions diagnosed by the health care provider either through clinical diagnosis, morphological diagnosis or clinical autopsy. The cancer notification is submitted by the health care provider in accordance with the National Board of Health and Welfare's regulations and general advice to the local RCC for coding of tumour diagnoses and quality control. Data from the previous calendar year, including updates to previous years, are submitted annually by the RCC to the National Board of Health and Welfare no later than 31 October. Data regarding the county and municipality in which the person is registered are provided by the RCC. These data are reconciled with the source register RTB, provided by Statistics Sweden, while additional information, such as citizenship and date of entry/exit, is added to the Register.

F2.4.2 Measurement

Coding of tumour diagnoses takes place at the RCC. For each tumour, the date of diagnosis, location and morphology are recorded. Patients are identified by their personal ID number. Each individual tumour is also assigned a unique serial number. The main quality problem of the National Cancer Register is the non-response that occurs when health care organisations do not report diagnosed cancer cases.

F2.4.3 Defective deliveries

Item non-response occurs when the health care provider fails to report diagnosed cancer cases. Reported tumour cases are based on the cancer notification from the clinic (the so-called 'A notification') and from the histopathological analysis ('B notification'). This can lead to delays or non-response. A particularly problematic type of non-response occurs when there is neither a clinical notification nor a histopathological sample or tumour tissue from surgery, resulting in no notification from the laboratory. In these cases, the RCC does not know that there is a cancer case that should have been notified from the clinic and therefore cannot remind the clinic to make a cancer notification. Other instances of unrecorded cancer cases are when tumours are discovered during a forensic autopsy.

¹ Fritz, April, Percy, Constance, Jack, Andrew, Shanmugaratnam, Kanagaratnam, Sobin, Leslie H. et al. (2000). International classification of diseases for oncology, 3rd ed. World Health Organization. <https://apps.who.int/iris/handle/10665/42344>

F2.5 Processing with review

F2.5.1 Coding

The location of each tumour in the National Cancer Register is coded by the RCC in each region according to the WHO's framework for classification of tumours and tumour-like conditions, *The International Classification of Diseases for Oncology*. Since 2019, version 3.2 (ICD-O/3.2) is used². In order to follow development over time, data on each tumour are recorded and translated according to previous classifications (ICD-O/2, ICD-9 and ICD-7) (see Figure 1). Since 2019, the histopathological diagnosis is encoded by a five-digit morphology code (SNOMED) according to ICD-O/3.2 and, in parallel, using previous WHO classification recommendations (C24 and SNOMED according to ICD-O/2). A detailed description of the codes used for each location and morphology coding manual is available in the publication "*Kodning i Cancerregistret*".³

Figure 1 Timeline for the introduction of classification codes for tumour location and morphology.

Location codes:

1958	1987	1993	2005
ICD-7			
	ICD-9		
		ICD-O/2	
			ICD-O/3

Morphology codes:

1958	1993	2005
C24		
	Morphology code/SNOMED (ICD-O/2)	
		Morphology code/SNOMED (ICD-O/3)

F2.5.2 Duplicate check

Duplicate checks are made at the RCC and again during the acceptance test after submission to the National Board of Health and Welfare. Each record in the Register thus represents data on a unique new tumour or tumour-like condition, and each record is therefore assigned a unique serial number.

F2.5.3 Reasonableness check

Extensive quality assurance takes place at the RCC, which collects and codes the cancer notifications before they are sent to the National Board of Health and Welfare. After delivery by RCC to the National Board of Health and Welfare of the previous calendar year's stock no later than 31 October each year, a so-called acceptance test is carried out, including reasonability tests that are performed with regard to selected variables to examine delivery quality. The acceptance test

² Fritz, April, Percy, Constance, Jack, Andrew, Shanmugaratnam, Kanagaratnam, Sobin, Leslie H. et al. (2000). International classification of diseases for oncology, 3rd ed. World Health Organization. <https://apps.who.int/iris/handle/10665/42344>

³ *Kodning i cancerregistret 2022, Arbetsdokument för personal vid regionala cancercentra (RCC) (Coding in the Cancer Register 2022, Working document for Regional Cancer Centre staff), Article number 2022-3-7793* <https://www.socialstyrelsen.se/globalassets/sharepoint-dokument/artikelkatalog/ovrigt/2022-3-7793.pdf>

checks that data from all regions have been received, that the benignity variable is consistent with ICD-7 and PAD variables, and that data on gender and place of registration are included. It also examines the reasonableness of the distribution of diagnoses with a strong link to gender, such as prostate and breast cancer. Variables that are expected to fall within a specific range are checked, such as the basis of diagnosis (1-8) and ICD-7 (140-208). Variables that are expected to have a specific length are checked. These include PAD, which is expected to consist of three digits, and ICD-O/2 and ICD-O/3 location codes, which are expected to consist of four characters. In summary, checks are performed both for patient-related and geographical variables, as well as for tumour variables related to morphology and location. In addition, checks are made during the production of the statistics, whereby tumour trends by location are visually inspected for unexpected trend breaks, etc., that might indicate errors in the data, in which case further investigation is required.

F2.5.4 Imputations

Date of death is taken from the National Cause of Death Register and Statistics Sweden and added to the National Cancer Register. In some cases, the precise day of death is missing. It is then set to the 15th of that month. If both the month and day of death are missing, the date of death is set to 2 July of that year.

F2.5.5 Model-based calculations

Not applicable.

F2.5.6 Comparisons with other registers and data sources

Upon merging⁴ the National Cancer Register with the National Cause of Death Register for the reporting year 1998, non-response in the National Cancer Register was estimated at about four per cent.⁵ However, non-response rates were higher for some cancers and in older age groups. Non-response has been shown to be high for cancer diagnoses in the lung (16%) and pancreas (34%).⁶ This has also been described in the fact sheet "Non-response in the National Cancer Register upon comparison with cause of death certificates"⁷. Information on the date of death is obtained from both the National Cause of Death Register and Statistics Sweden.

F3 Implementation

F3.1 Quantitative information

Each year, over 70,000 malignant tumours are diagnosed by healthcare providers in Sweden (see Figure 2). The most common diagnoses are breast cancer and

⁴ Merging involves linking the data in two or more different registers containing different types of data. For example, data regarding an individual's dispensed medicines in the National Prescribed Drug Register can be linked to any diagnoses of the same individual in the National Patient Register. A key variable present in both registers is used to link the correct data to each other. In the case of registers containing individual data, such as health data registers, this key variable is usually the personal ID number. Cf. recital 157 of the GDPR.

⁵ Barlow L, Westergren K, Holmberg L, Talbäck M. The completeness of the Swedish Cancer Register: a sample survey for year 1998. *Acta Oncol.* 2009;48(1):27-33. doi: 10.1080/02841860802247664. PMID: 18767000

⁶ Lambe M, Wigertz A, Sandin F, Holmberg E, Amsler-Nordin S, Andersson TM, Pettersson D. Estimates of lung and pancreatic cancer survival in Sweden with and without inclusion of death certificate initiated (DCI) cases. *Acta Oncol.* 2020 Nov;59(11):1322-1328. doi: 10.1080/0284186X.2020.1826572. Epub 2020 Oct 16. PMID: 33063588.

⁷ *Bortfall i cancerregistret vid jämförelse med dödsorsaksintyg*, Art. no.: 2021-9- 7530| Published: 07/09/2021 <https://www.socialstyrelsen.se/globalassets/sharepoint-dokument/artikelkatalog/statistik/2021-9-7530.pdf>

prostate cancer, which together account for around 20,000 cases annually (Figure 3).

Figure 2. Cancer incidence and mortality in Sweden over time. Number of diagnosed tumors and cancer deaths, 1970–2021

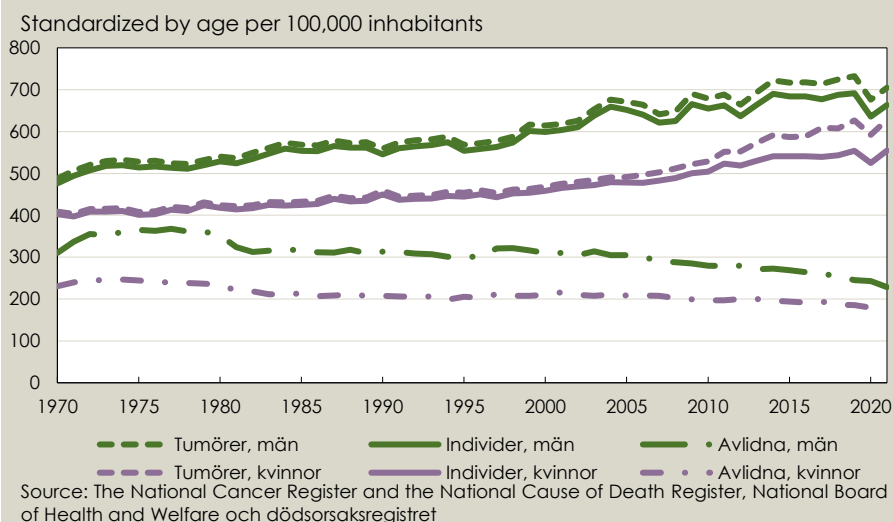
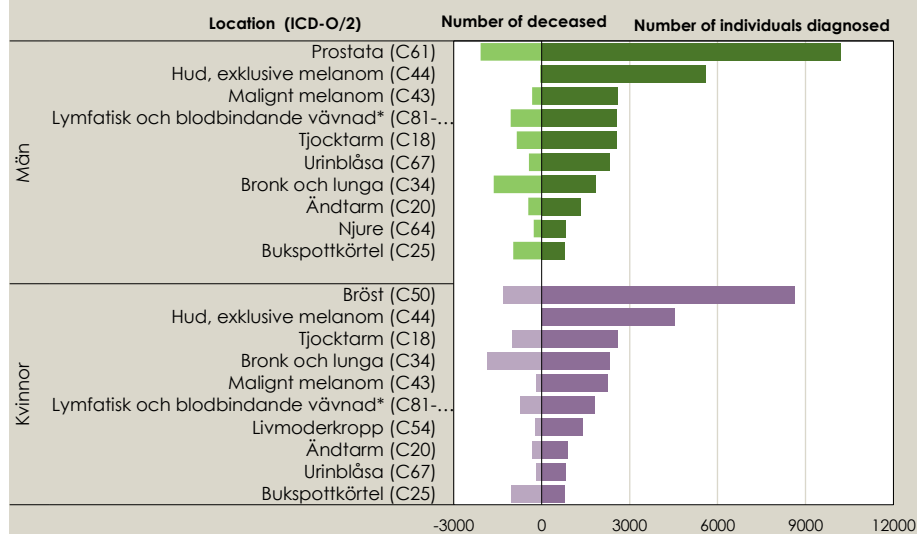


Figure 3. The ten most common forms of cancer, 2021

Number of individuals diagnosed and deceased



* Including lymphomas, leukemias, and related forms of cancer.

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

F3.2 Deviations from the design

No significant deviations from the design have been made.

Statistical register quality

K1 Relevance

The Swedish National Cancer Register contains data on tumours diagnosed in Swedish health care institutions since the Register was launched in 1958. The Register is a tumour-based registry, where each entry is a newly discovered tumour or tumour-like condition.

K1.1 Objectives and information needs

K1.1.1 Register objective

The main purpose of the Register is to enable register-based statistics on cancer incidence in Sweden, and to provide a basis for monitoring, evaluation and quality assurance of health care, and for research and epidemiological studies. The Register is used in commissioned activities at the National Board of Health and Welfare, and for statistical assignments, and is disclosed at individual level for research.

K1.1.2 Information needs of register users

Statistics are produced to monitor cancer incidence, cancer prevalence and cancer survival in Sweden over time. Statistics on tumour incidence, prevalence and survival are needed for research, monitoring, prevention and allocation of healthcare resources.

K1.2 Register content

The target population consists of all people diagnosed with a tumour or tumour-like condition by a health care provider in Sweden. The information to be reported is stated in the National Board of Health and Welfare's Regulations and general guidelines on the obligation to provide information to the National Board of Health and Welfare's National Cancer Register (HSLF-FS 2016:7). Key target variables are those related to the location, morphology, date of diagnosis and stage of the tumour, as well as information about the patient, such as age, gender and place of registration, and the health care facility where the diagnosis was made.

K1.2.1 Object and population

The target and observation objects of the Register are data on tumours and tumour-like conditions diagnosed by health care providers in Sweden. The target population consists of people in the Swedish population who have been diagnosed with a tumour at a Swedish health care facility. Some cancer reporting groups are linked to gender-specific organs. In the National Cancer Register, there are occasional cases where the legal gender of an individual does not match the gender-specific diagnosis. Currently, data on these cases are excluded from the statistics within the gender-specific reporting groups. The official statistics report data on malignant tumours and a selection of certain non-malignant tumours, unless otherwise stated.

K1.2.2 Variables

The most important variables in the National Cancer Register are those related to the diagnosis of tumours in terms of type, location and morphology, as well as the date

of diagnosis. Variables for the location and morphology of the tumour are coded in RCC according to coding instructions developed by the WHO; since 2005, these are found in ICD-O/3.2. When a new tumour is registered, the tumour is also coded according to previous instructions, to enable the production of longer time series. Other important tumour-descriptive variables are those related to the stage and extent of the tumour. These are coded according to the TNM (Tumour-Node-Metastasis) Classification of Malignant Tumours. The TNM variables thus enable tumour-specific stage stratification. Furthermore, the Register contains data related to the patient such as age, gender and place of registration. The Register also includes variables with information on the health care facility where the diagnosis was made. For longitudinal follow-up, such as survival analyses, the Register contains information on the date of death and immigration or emigration. A complete list of variables can be found on the National Board of Health and Welfare's National Cancer Register website.⁸

K1.2.3 Reference times

The National Cancer Register is produced once per year, shortly after the publication of the official statistics. The reference period refers to full calendar years. Its production is preceded by an annual reporting of data on tumour diagnoses from the RCC in each region to the National Board of Health and Welfare by 31 October each year.

K2 Reliability

K2.1 Overall reliability

The reliability of the National Cancer Register is generally good, with high coverage and accurate coding that in most cases (about 99%) is also based on histopathological information.⁹ Non-response varies with the location of the tumour, and may in some cases affect the statistics. The Register is widely used by other public agencies, stakeholder organisations and researchers. The broad user base makes it likely that major deficiencies in the Register would be detected. The exception to the generally high reliability relates to non-response, particularly for tumours detected at advanced stages. The non-response rate is also higher for older patients.

K2.2 Sources of uncertainty

The main quality problem of the National Cancer Register is the non-response that occurs when health care organisations do not report diagnosed cancer cases. The RCC collects cancer diagnoses from different diagnosing organisations such as clinical organisations (the so-called 'A notification') and pathology laboratories ('B notification'). After quality control and coding of tumour diagnoses, data are delivered annually to the National Board of Health and Welfare. There is also a certain delay in reporting and a certain amount of non-response, as RCCs sometimes wait for histopathologies (Figure 4). Entries whose delivery to the National Board of Health and Welfare were delayed are not evenly distributed between tumour locations, and for some cancer types, such as Skin (C44, large number) or Digestive tract (C26, high proportion), a delay in the number of records reported to the National Board of Health and Welfare for the statistical year 2021 was observed (see Figure 5).

⁸<https://www.socialstyrelsen.se/en/statistics-and-data/registers/national-cancer-register/>

⁹ L, Westergren K, Holmberg L, Talbäck M. The completeness of the Swedish Cancer Register: a sample survey for year 1998. *Acta Oncol.* 2009;48(1):27-33. doi: 10.1080/02841860802247664. PMID: 18767000

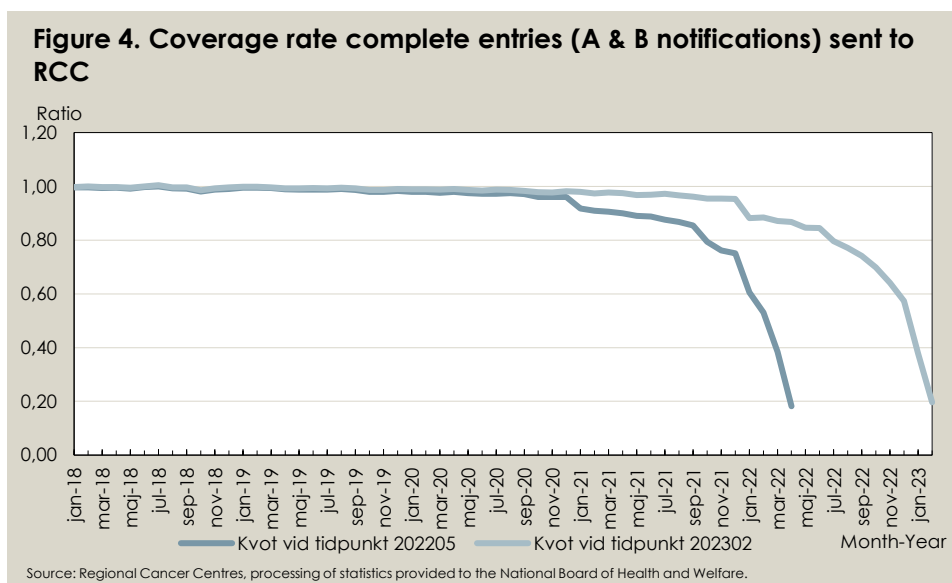
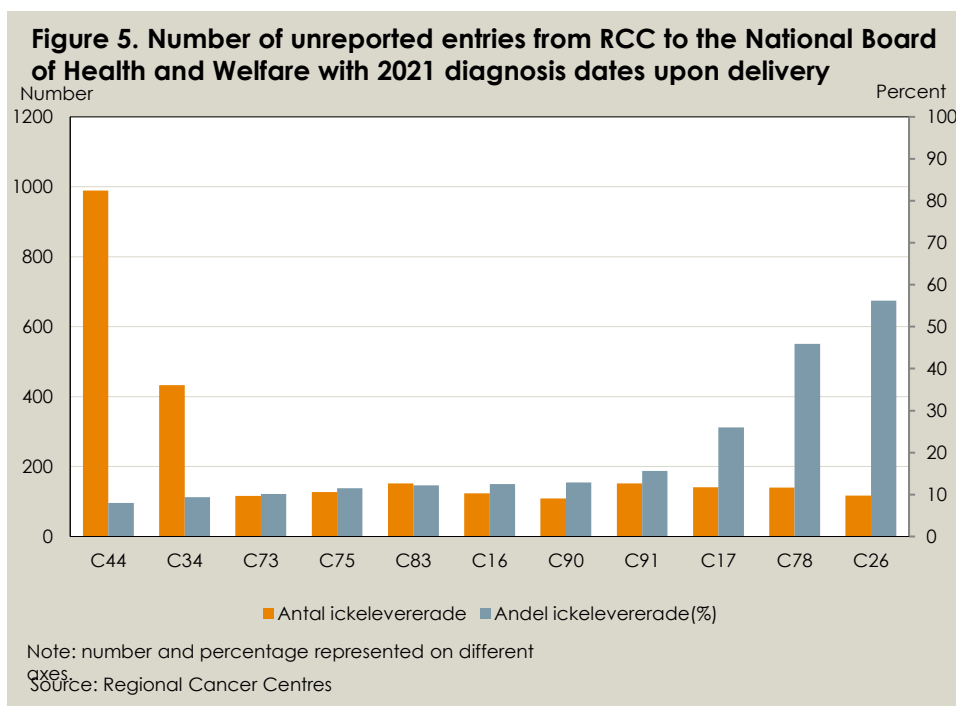


Figure 5 Number and proportion of entries from reporting year 2021 not reported to the National Board of Health and Welfare by RCC on 1 November 2022, being incomplete on the day of delivery. Tumour locations with the highest number and percentage of undelivered entries are displayed. The locations are represented by ICD-O/2 codes.¹⁰



At greatest risk of non-response are tumours diagnosed at advanced stages in elderly patients. Notification is less likely to be made for such patients because they often receive neither curative nor palliative treatment, but only palliative

¹⁰C44. Skin, C34: Trachea (Bronchus) and Lung, C73: Thyroid gland (Thyreoidea), C75: Other endocrine glands, C83: B-cell lymphoma, C16: Stomach (ventricle), C90: Plasmacytoma, C91: Lymphatic leukaemia, C17: Small intestine, C78: Secondary malignant tumour of the respiratory and digestive system, C26: Digestive organs.

care. Invasive sampling of the tumour thus does not benefit the patient, meaning that no lab pathology report results. Examples of such cancers where non-response is significant are pancreatic and lung cancer, where annually about 370 identified cases in the National Cause of Death Register are never reported to the National Cancer Register. At present, there is no legal basis for following up on information in death certificates for the purpose of supplementing the National Cancer Register, a procedure that is standard practice in most other countries' cancer registries.

There is a backlog in reporting to the National Cancer Register. When the 2016 statistics were published, the total number of tumours that year was just over 64,100. When the 2017 statistics were published, the same figure for 2016 was almost 67,400, an increase of just over five per cent. The numbers for the last reporting year are generally underestimated and should therefore be considered with some caution. The size of the backlog varies between different cancer locations and is referred to in connection with tables and graphs in the official statistics where appropriate. Table 1 shows the number of tumours per location diagnosed before reporting year 2021.

Table 1. Number of tumours per location for the 2021 publication of the official statistics for cancer diagnosed before reporting year 2021.

Location (ICD-7 code)	Number	Percent
Male genitalia (179)	26	9.3
Multiple myeloma, plasmacytoma(203)	76	9.4
Liver/bile ducts (155)	158	10.4
Lymphatic/blood-forming tissue (200)	305	13.3
Myeloid leukaemia (205)	150	14.7
Connective and other soft tissue (197)	54	14.8
Kidney/renal pelvis (180)	274	14.9
Other leukaemia and unspec. (207)	58	15.8
Lymphatic leukaemia (204)	158	16.8
Other/unspecified area (199)	166	17.7
Brain and other nervous system (193)	334	19.3
Polycythemia vera (208)	57	19.4
Endocrine gland (195)	281	19.4
Small intestine (152)	107	19.6
Lymphatic tissue tumour (202)	53	21.1
Myelofibrosis (209)	52	22.9
Liver cancer, unspecified (156)	26	37.7

Footnote: The denominator is all location -specific new tumours reported to the Register. The Table shows cancer location with a reporting rate in years prior to the reporting year greater than 7% and more than 15 tumours.

K2.2.1 Coverage

The National Cancer Register is based on the ongoing reporting of diagnosed tumours received from health care providers to the RCC in each health care region. Coverage errors occur when a tumour is not diagnosed in the health care system, or when a diagnosed tumour is not reported to the National Cancer Register.

K2.2.2 Measurement

When a tumour is diagnosed by a health care provider in Sweden, information about the tumour is then sent in plain text to the RCC, where the information regarding location and morphology is coded according to the current classification and also according to previous classification instructions. Thus, an accurate coding procedure requires that sufficiently detailed information is transmitted from health care providers to the RCC. To ensure a high level of classification, there are regular reconciliation meetings where coding issues are discussed and where all RCCs and the National Board of Health and Welfare participate.

K2.2.3 Non-response

Upon merging the National Cancer Register with the National Cause of Death Register, non-response in the National Cancer Register was estimated at about four per cent.¹¹ However, non-response rates were higher for some cancers and in older age groups. For breast cancer, for example, the non-response rate is very low, while hundreds of cases of pancreatic and lung cancer reported annually to the National Cause of Death Register have never been reported to the National Cancer Register. Non-response of a similar magnitude is shown in the report "Non-response in the National Cancer Register upon comparison with cause of death certificates".¹² The report also highlights differences in non-response between different cancer types. Tumours detected during a forensic autopsy are not subject to the notification requirement.

K2.2.4 Data processing

Data from the health care provider are reported to the RCC in each region to be checked, coded and registered. Checks and processing are also carried out at the National Board of Health and Welfare. The National Cancer Register is a living register that is updated annually with new or changed diagnoses that are submitted to the National Board of Health and Welfare via the RCC from health care providers.

K2.2.5 Modelling assumptions

Not applicable.

K2.3 Provisional register compared to final register

This information on the register refers only to the final observation register.

K3 Timeliness and punctuality

K3.1 Preparation time

The production time for the National Cancer Register is approximately 12 months after the end of the reference year.

K3.2 Frequency

The National Cancer Register is produced annually after the publication of the official statistics.

¹¹ Barlow L, Westergren K, Holmberg L, Talbäck M. The completeness of the Swedish Cancer Register: a sample survey for year 1998. *Acta Oncol.* 2009;48(1):27-33. doi: 10.1080/02841860802247664. PMID: 18767000

¹² *Bortfall i cancerregistret vid jämförelse med dödsorsaksintyg*. Art. no.: 2021-9- 7530| Published: 07/09/2021 <https://www.socialstyrelsen.se/globalassets/sharepoint-dokument/artikelkatalog/statistik/2021-9-7530.pdf>

K3.3 Punctuality

Availability has been punctual. The Register has been made available no later than three months after the publication of the official statistics.

K4 Accessibility and clarity

K4.1 Access to the register

All information in the National Cancer Register is protected by confidentiality (see also section U1). However, it is possible to disclose data for purposes including research, but only on a case-by-case basis. Furthermore, the use of the register data is limited to statistics, research and epidemiological studies, and monitoring and evaluation. Data subjects have the right to access their personal data. The National Board of Health and Welfare's statistical activities are subject to statistical confidentiality according to the Public Access to Information and Secrecy Act (2009:400). Automated processing of personal data is also subject to the rules of the General Data Protection Regulation. See also section U1.

Aggregated data from the register are also available in the official statistics, in the National Board of Health and Welfare's statistics database, and through our commissioning activities.

K4.2 Dissemination of information

Detailed information about the National Cancer Register, including detailed descriptions of variables and variable sets, can be found at socialstyrelsen.se. The official statistics based on the register are published annually. The publication date is indicated in the publication calendar of the National Board of Health and Welfare.¹³

K4.3 Documentation

The Register is comprehensively documented on socialstyrelsen.se, including detailed descriptions of variables and value sets.¹⁴

K5 Comparability and interoperability

K5.1 Comparability over time

The Swedish Cancer Register has existed since 1958. All newly registered tumours are also coded according to older instructions, allowing easy extraction of long time series. The National Board of Health and Welfare follows the WHO international coding instructions for the classification of tumours. Incremental changes in coding instructions can therefore lead to changes in the statistics over time. For example, when the Register was established, the ICD-7 classification was used for the location of the tumour. In 1987, ICD-9 was introduced. As of 1993, a more precise, cancer-specific classification (ICD-O/2) was applied. Since 2005, the latest cancer-specific classification ICD-O/3 has been applied. The latest version, ICD-O/3.2, was approved in 2019. The histopathological conditions of the tumour were initially coded according to C24 and then changed to the morphology code according to ICD-O/2 in 1993, and then to the current morphology classification, ICD-O/3, in 2005. When registering new tumours at

¹³ <https://www.socialstyrelsen.se/statistik-och-data/statistik/publiceringskalender-for-statistik/>

¹⁴ <https://www.socialstyrelsen.se/en/statistics-and-data/registers/national-cancer-register/>

RCC, they are classified according to both the latest coding instruction and previous instructions regarding both the location of the tumour and its histopathological diagnosis, allowing easy access to long time series. Some of the main changes in the coding instruction are described in Figure 1 in section 2.5.1.

K5.2 Interoperability with other registers

The National Cancer Register contains individual-based data, which allows the linking of cancer statistics with, for example, the National Cause of Death Register, or data from other health data registries, such as the National Patient Registry or the National Prescribed Drug Register. This allows for questions related to, e.g., tumour-specific mortality.

General information

U1 Confidentiality and personal data processing

In the special activities of public agencies for the production of statistics, confidentiality applies in accordance with Chapter 24, Section 8 of the Public Access to Information and Secrecy Act (2009:400). However, information needed for research and statistical purposes, as well as information that is not directly attributable to an individual through his or her name, other identity code or similar relationship, may be disclosed if it is clear that the information can be disclosed without causing damage or harm to the individual or someone close to him or her.

When processing personal data, i.e., information that can be directly or indirectly attributed to a living person, the General Data Protection Regulation¹⁵ and the Regulation (2018:218) containing supplementary provisions to the EU General Data Protection Regulation apply.

In addition, the Act regarding official statistics (2001:99) (, the Ordinance regarding official statistics (2001:100) and the Health Data Register Act (1998:543) apply to the processing of personal data.

U2 Retention and data erasure

The National Cancer Register is a register where personal data must be exempt from data erasure. The register is covered by the Swedish National Archives' Regulations (RA-MS 2020:22), regarding exemptions from data erasure and data erasure at the National Board of Health and Welfare. Primary data, i.e., the basis for the register, may be erased five years after the basis has been received by the public agency.

The register is a so-called living register, which means that continuous updates can change data even historically. Immediate erasure of incorrect data is permitted under RA-MS 2020:22, which means that earlier versions of the register are generally not saved by the National Board of Health and Welfare.

The data are archived through 1976 at the National Board of Health and Welfare and, after 1977, at the RCC of each health care region.

¹⁵ Regulation (EU) 2016/679 of the European Parliament and the Council of 27 April 2016 on the protection of natural persons with regard to the processing of personal data and on the free movement of such data, and repealing Directive 95/46/EC (General Data Protection Regulation).

U3 Obligation to give information

The obligation to report tumours and tumour-like conditions to the National Board of Health and Welfare applies to all health care providers in accordance with the Health Data Register Act (1998:543), the Ordinance on Cancer registers at the National Board of Health and Welfare (2001:709), and the National Board of Health and Welfare's regulation and general advices (HSLF-FS 2016:7) on the obligation to report to the National Board of Health and Welfare's cancer register. In addition, the Act regarding official statistics (2001:99) and the Ordinance regarding official statistics (2001:100) impose an obligation to provide information, which means that public agencies must provide the information needed to produce statistics.

U4 EU regulation and international reporting

Data from the National Cancer Register are reported annually to NORDCAN, the Nordic countries' cooperation organisation for cancer registries.¹⁶ Data are also provided to the publication '*Cancer incidence on five continents*' published by the International Agency for Research on Cancer (IARC) every five years (last publication in 2021).¹⁷ Statistics are also provided to other producers of international statistics, such as Eurostat and the OECD.

U5 History

The history of the Register is briefly described in section K5.1 and in greater detail in documentation on the Register's website.¹⁸

U6 Contact details

Questions about the National Cancer Register can be sent to the functional mailbox of the Cause of Death, Cancer and Dental Health Statistics team.

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¹⁶ Larønningen S, Ferlay J, Beydogan H, Bray F, Engholm G, Ervik M, Gulbrandsen J, Hansen HL, Hansen HM, Johannessen TB, Kristensen S, Kristiansen MF, Kønig SM, Lam F, Laversanne M, Miettinen J, Mørch LS, Ólafsdóttir E, Óskarsson O, Pejicic S, Petterson D, Skog A, Skovlund CW, Tanskanen T, Tian H, Virtanen A, Aagnes B, Storm HH (2022). NORDCAN: Cancer Incidence, Mortality, Prevalence and Survival in the Nordic Countries, Version 9.2 (23.06.2022). Association of the Nordic Cancer Registries. Cancer Registry of Norway. Available from: <https://nordcan.iarc.fr/>.

¹⁷ Cancer Incidence in Five Continents Vol. XI, 2021, F. Bray, M. Colombet, L. Mery, M. Piñeros, A. Znaor, R. Zanetti and J. Ferlay, IARC Scientific Publications No. 166

¹⁸<https://www.socialstyrelsen.se/en/statistics-and-data/registers/national-cancer-register/>