

Department of Registers and Statistics
Jeroen de Munter

Statistical register's production and quality

National Cause of Death Register

The National Cause of Death Register contains information on all deceased persons in Sweden, including deaths of people registered in Sweden who die abroad, and their cause of death.

Reference period

Annual presentation of all deceased persons in Sweden and their cause of death in the last year, and for time periods 1997-, and historical material for the periods 1987-1996, 1969-1986, 1961-1968 and 1952-1957. Deceased persons not registered in Sweden are included in the Register from 1 January 2012. The Register is partially a living register and receives updates with late death certificates, and people registered abroad, about 1.5 years after publication.

Table of contents

Statistical register's production and quality	1
National Cause of Death Register	1
Reference period	1
Production of the statistical register	4
F1 Context of the statistical register	4
F2 Design	4
F2.1 Outline of register content	4
F2.2 Data sources.....	4
F2.3 Time frame	4
F2.4 Collection procedure.....	5
F2.5 Processing with review	6
F3 Implementation	7
F3.1 Quantitative information.....	7
F3.2 Deviations from the design.....	7
Statistical register quality	7
K1 Relevance	7
K1.1 Objectives and information needs.....	7
K1.2 Register content	8
K2 Reliability	9
K2.1 Overall reliability	9
K2.2 Sources of uncertainty.....	9
K2.3 Provisional register compared to final register	13
K3 Timeliness and punctuality	13
K3.1 Preparation time	13
K3.2 Frequency.....	14
K3.3 Punctuality	14
K4 Accessibility and clarity	14
K4.1 Access to the register	14
K4.2 Dissemination of information	14
K4.3 Documentation.....	14
K5 Comparability and interoperability	14
K5.1 Comparability over time	14
K5.2 Interoperability with other registers	15
General information	16
U1 Confidentiality and personal data processing	16
U2 Retention and data erasure	16
U3 Obligation to give information	16
U4 International reporting	17
U5 History	17

U6 Contact details **17**
Version history **17**

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 statistics and research on health care and social services. The National Cause of Death Register (DORS) contains individual data on all deceased persons in Sweden and their cause of death. The purpose of DORS is to enable register-based statistics on the causes of death in the population.

The data in the Register are used as a basis for Sweden's official statistics on cause of death, international statistics on cause of death, prevention and development work in health care and research.

F2 Design

F2.1 Outline of register content

DORS contains data on the date and place of death, underlying cause of death, contributing causes of death, external injuries or causes, and other background factors (e.g., autopsy) on which cause of death data are based. DORS does not contain data on stillbirths. Persons not registered in Sweden who have died in Sweden are included in the Register, albeit with some delay.

F2.2 Data sources

DORS is based on the cause-of-death certificate¹, which contains information on the individual's cause of death. Data regarding country of birth, and county and municipality of registration, etc., are taken from the source register RTB (the Total Population Register) provided by Statistics Sweden (SCB).

F2.3 Time frame

DORS is produced once a year with cause-of-death data from the previous calendar year, also known as the reporting period.

Cause-of-death certificates, which contain information on the cause of death, are continuously reported to the National Board of Health and Welfare. The collection of the new annual stock is finalised about four to five months after the end of the reporting period, after most cause-of-death certificates for this period have been received.

Late certificates, i.e., certificates received after the collection has been completed, and deceased persons not registered in Sweden for the current reporting period, are added to the Register but with a certain delay, a so called "correction". The completion of such deaths takes place once a year and refers to the previous reporting period. Thus, in 2020, deaths that occurred in 2019 were published, and the year 2018 received a correction at the end of 2020.

¹ Select 'Cause of Death Register' at <https://www.socialstyrelsen.se/statistik-och-data/register/lamna-uppgifter-till-register/>

F2.4 Collection procedure

F2.4.1 Data collection methods and data providers

When a person dies, the death is reported to the Tax Agency by the doctor sending a death certificate. According to the Funeral Act (1990:1144) and the associated regulation (1990:1147), the doctor confirming the death is obliged to ensure that a cause-of-death certificate is also issued and sent to the National Board of Health and Welfare. The task of issuing the cause-of-death certificate can be delegated to another doctor who has more information about the deceased.

The death certificate is the basis for the notifications of deceased persons delivered by the Swedish Tax Agency to the National Board of Health and Welfare every Tuesday through Saturday. These alerts are then used to check the completeness of the register production. The cause-of-death certificate must be sent to the National Board of Health and Welfare within three weeks of the death. The certificate can be issued on a paper form, directly from medical record systems or digitally via a certificate service (WebCert) or via the National Board of Health and Welfare's website. After 2022, issuing a cause-of-death certificate via Emortis, another electronic service, will no longer be possible.

In cases where the police have ordered a forensic autopsy (where it cannot be determined whether the deceased died of natural causes or injury, or where the deceased has not been identified), the National Board of Forensic Medicine (RMV) sends a certificate of cause of death to the National Board of Health and Welfare. This delivery is usually once a month, with possible extra deliveries before the end of the collection.

When the paper certificates are received by the National Board of Health and Welfare, they are digitised by scanning, OCR reading and manual validation of the text expressions. The certificates can then be loaded into the production system for further processing with classification of the diagnostic expressions and selection of the underlying cause of death. The electronic certificates and files from the RMV can be directly loaded into the production system.

F2.4.2 Measurement

The deceased are identified by personal ID number. Unregistered persons are identified by date of birth, coordination number, or personal ID number (emigrants). The quality of the Register is mainly determined by the individual doctors who write the cause-of-death certificates. The cause-of-death certificate provides information on how to fill in the different fields. All relevant diagnoses or injuries that led to the death must be listed in text, for later coding and classification by the National Board of Health and Welfare. It is unclear what review procedures are used by individual doctors. It is also unclear to what extent the true value requested differs from that submitted by the informant to the National Board of Health and Welfare.

F2.4.3 Defective deliveries

Object non-response occurs when the cause-of-death certificate is completely missing (classified with ICD-10 code R99.9), e.g., when doctors fail to send a cause-of-death certificate. If the cause-of-death certificate is missing, the first reminder is sent after about eight weeks. When registered residents of Sweden who have died abroad do not receive a death certificate from abroad, it is classified as R99.8.

Partial non-response occurs at a slightly higher rate for some accounting variables for unregistered and deceased abroad, due to missing information from the national population register and quality deficiencies in cause-of-death certificates from abroad.

F2.5 Processing with review

F2.5.1 Coding

Variable coding in the Register is described in a document on the website of the National Board of Health and Welfare on the National Cause of Death Register². DORS applies the WHO international framework for classifying all causes of death on the certificates and selecting the underlying cause of death. The classification uses the latest updated English version of ICD-10, which has undergone annual revisions until 2019. The international ICD-10 differs slightly from the Swedish ICD-10-SE. National specialisation codes are not included in the international ICD-10, and Swedish proposals for code changes are implemented some years earlier than the international version. In addition, Volume 3 of ICD-10 has not been translated into Swedish, which is needed for the classification of causes of death. Deaths that are identified through the national population register, but for which there is no cause-of-death certificate, received code R99.9.

F2.5.2 Duplicate check

Duplicate checks are carried out in comparison with previous years and at certificate-level to ensure that deaths are in the correct year.

F2.5.3 Reasonableness check

Reasonableness checks in the target variables are done against previous years and by age distribution. Specifically for the underlying cause of death, there are reasonableness checks during classification, i.e., some codes may not be applied in certain age ranges, and some codes are gender-specific. The double coding for external causes (Chapter 19) must agree with the underlying cause of death. Extra checks are carried out during final production and for rare diseases. Reasonableness checks are also carried out on the content of the underlying cause-of-death variable by chapter level and other accounting variables before the publication of the Register.

F2.5.4 Imputations

Not applicable

F2.5.5 Model-based calculations

Not applicable

F2.5.6 Comparisons with other registers and data sources

Comparison with SCB's RTB shows that DORS has more registered deaths, but the difference is small. For example, in 2019, RTB recorded 88,766 deaths, while DORS recorded 88,822 deaths of the registered population. This difference arises because RTB waits for notifications of deaths 4-5 weeks after 31 December, while DORS has a significantly longer lead time, given the fact that cause-of-death certificates take longer to produce than death certificates. There

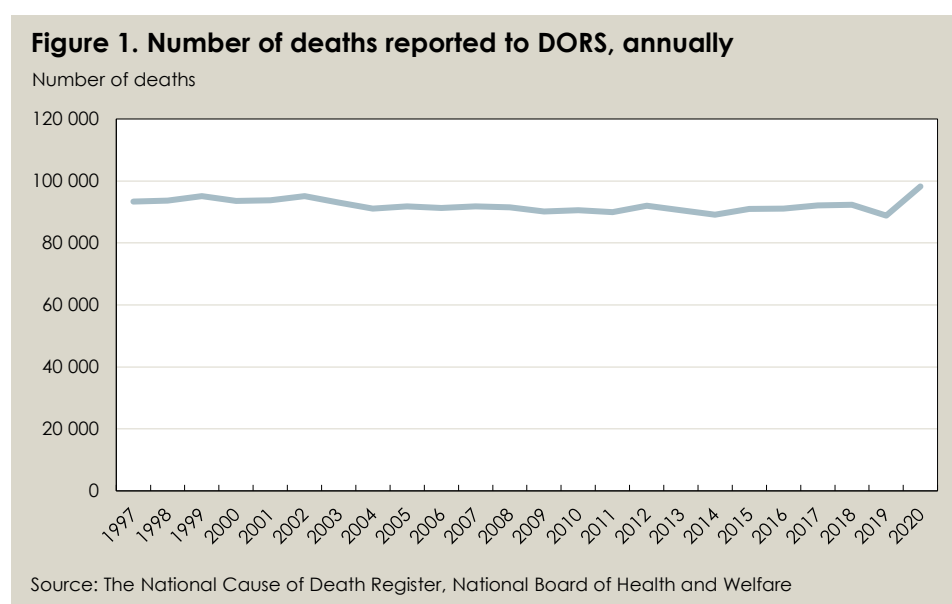
² <https://www.socialstyrelsen.se/statistik-och-data/statistik/alla-statistikamnen/dodsorsaker/>

is also a slight increase in the number of deaths added to the Register during correction, mainly for unregistered persons but also for new cause-of-death certificates (notified late).

F3 Implementation

F3.1 Quantitative information

Each year, about 90,000 people die in Sweden. 2020 was a special year due to the COVID-19 pandemic, which is reflected in the number of reported deaths (Figure 1).



F3.2 Deviations from the design

The production of DORS was accelerated, starting in 2020 (reporting year 2019), due to the pandemic. An earlier production of the Register resulted in more missing cause-of-death certificates at publication, and therefore the underlying cause of death was assigned R99.9 (certificate missing) in the publication of official statistics on causes of death. An indirect consequence of an earlier production of the Register is that more entries will be added retrospectively in the 2019 compilation, compared to previous years. This pattern will continue going forward, with publication about six months after the end of the reporting period compared to the production time, in previous years, of about nine months.

Statistical register quality

K1 Relevance

K1.1 Objectives and information needs

K1.1.1 Register objective

The main purpose of the Register is to enable register-based cause-of-death statistics 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, for tabular work, and, for researchers, at the micro level.

K1.1.2 Information needs of register users

Statistics are produced to evaluate health services and prioritise preventive measures. Statistics on the causes of death in the population are needed, among other things, for population projections and the efficient allocation of society's resources.

K1.2 Register content

The target population consists of all persons who died in Sweden and registered individuals who died abroad at the reference time of the Register. The main target variables of the Register are the underlying cause of death, and multiple causes of death that include all diseases and injuries stated on the certificate.

K1.2.1 Object and population

The target and observation objects of the Register are deaths of individuals.

The target population consists of all persons who died in Sweden and registered persons who died abroad at the reference date of the Register, if the laws, ordinances and other rules governing population registration were observed correctly.

K1.2.2 Variables

The main target variables of DORS are underlying cause of death and multiple causes of death. The Register also contains reporting variables that describe each death more specifically, such as age, gender, date of death, etc. If the cause of death is an external cause, there is also a target variable describing the main injury in the so-called "Chapter 19" variable.

The underlying cause of death is selected from the cause-of-death certificate according to the international coding instructions established by the WHO. The underlying cause of death is the disease or injury that initiates a chain of disease events leading directly to death or the circumstances of the accident or act of violence that produced the fatal injury. The underlying cause of death thus has the greatest potential to prevent deaths through preventive and curative measures that will ultimately improve the health and longevity of the population. Observation variables are all diseases, conditions, and injuries that the responsible physician judged to be relevant to the death and recorded in the cause-of-death certificate. It also includes injuries resulting from hospitalisation (e.g., surgery) that may have contributed to the death.

A complete list of variables can be found on the National Board of Health and Welfare's National Cause of Death Register website.³

K1.2.3 Reference times

The National Cause of Death Register is produced once a year, covering the entire calendar year. Example: year 2018 contains all deceased persons in Sweden

³ <https://www.socialstyrelsen.se/statistik-och-data/statistik/alla-statistikammen/dodsorsaker/>

and the registered population who died abroad from 00/00/2018⁴ up to and including 12/31/2018. The 2018 reporting year will be published sometime in 2019. Late cause-of-death certificates, certificates that came to the National Board of Health and Welfare after the publication of the Register, and deceased persons not registered in 2018, are included in the Register the year after publication, in a so-called correction, i.e., in the example above, at the end of 2020.

K2 Reliability

K2.1 Overall reliability

The Register is considered to be very reliable, with high coverage and recorded causes of death corresponding to what the responsible doctor considered to be the cause of death. Statistics on causes of death from the Register should therefore be of high quality in most cases. The Register is used extensively by other statistics producers at the National Board of Health and Welfare and other public authorities and researchers, which means that major deficiencies in the Register would probably be detected.

However, there are exceptions to the high reliability, including deaths of the registered population that occur abroad.

Even too detailed statistical reporting of causes of death can be subject to significant errors. For example, statistics on specific causes of death for smaller geographical areas.

K2.2 Sources of uncertainty

The source that contributes most to the uncertainty is measurement.

K2.2.1 Coverage

The National Cause of Death Register receives regular information on deceased persons from the Swedish Tax Agency. Coverage errors occur when deaths are not reported to the Tax Agency. There are no estimates of coverage errors in the National Cause of Death Register, but the extent is considered to be very small.

K2.2.2 Measurement

The underlying cause of death is classified according to WHO instructions and is based on observational variables, i.e., information written by doctors on the cause-of-death certificate. The aim is to collect all medical conditions or injuries that were decisive or contributed to some extent to the death. If a doctor omits specific diseases or conditions that were significant to the death, measurement errors occur. Some validation studies have been published in scientific journals on the content of the National Cause of Death Register, although limited in scope and to specific causes of death. For example, researchers have compared information from the National Patient Register with information from the National Cause of Death Register⁵. There is currently no up-to-date overview of all validation studies that have been carried out on the National Cause of Death Register.

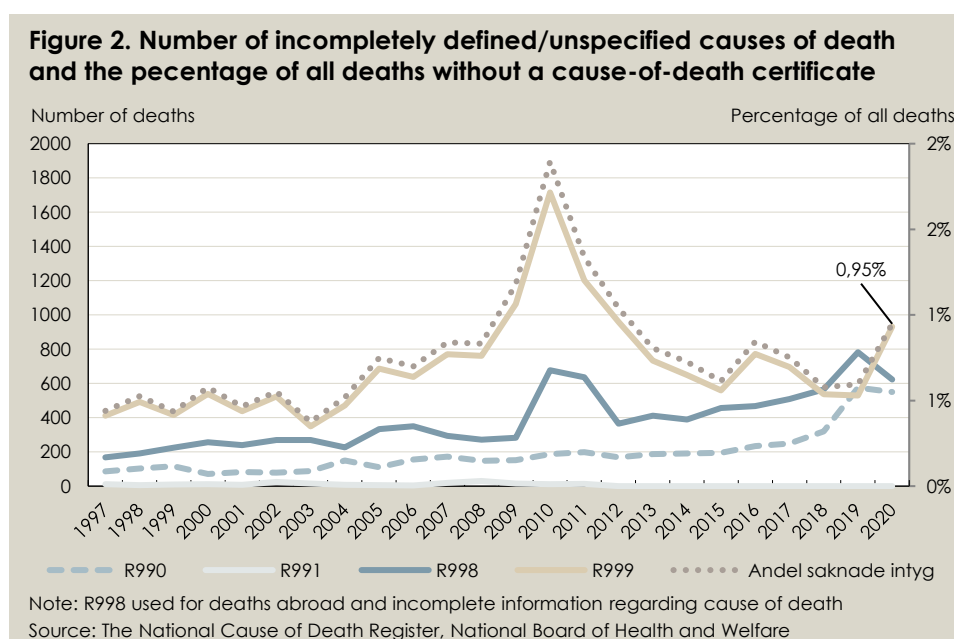
⁴ The date of death may contain an unknown month and/or day and will be filled in with zeros.

⁵ Rizzuto, D. Feldman, A. L. Karlsson, I.K. Dahl Aslan, A.K. Gatz, M. Pedersen, N.L. Detection of dementia cases in two Swedish health registers: A validation study. *Journal of Alzheimer's Disease* 61 (2018) 1301–1310

Another case where measurement errors can occur is in the substance module, which scans all text on the cause-of-death certificate from RMV and indexes substances. If a doctor writes "no methadone", or "no evidence of heroin", or "known history of heroin abuse", this substance may be included in the substance register. More information on the substance module and on specific measurement errors is available in previously published reports.⁶

K2.2.3 Non-response

If no cause-of-death certificate is submitted to the National Board of Health and Welfare, the underlying cause of death is set to R99.9 (Figure 2). Less than one per cent of all deaths have a missing cause-of-death certificate since 2013. The explanation for the peak in 2010 is the escalation of the production of the National Cause of Death Register. Other relevant R99 codes are R99.0 (Cause of death not determinable), and R99.8 (Documents received, cause-of-death information not included). R99.1 is no longer used since 2012, and R68.8 (Other specified general symptoms and signs of disease) is instead used for these deaths.



Some causes of death are unspecified according to the WHO. If a doctor uses only unspecified causes of death on the certificate, follow-up questions are sent if the person was under 65 years old (for 2021 annual stock). If no further information is received, the underlying cause of death is listed as unspecified.

⁶The National Board of Health and Welfare (2016). *Narkotikarelaterade dödsfall - En analys av 2014 års dödsfall och utveckling av den officiella statistiken*. Item no. 2016-2-32

Table 1. WHO's definition of codes considered insufficiently specified

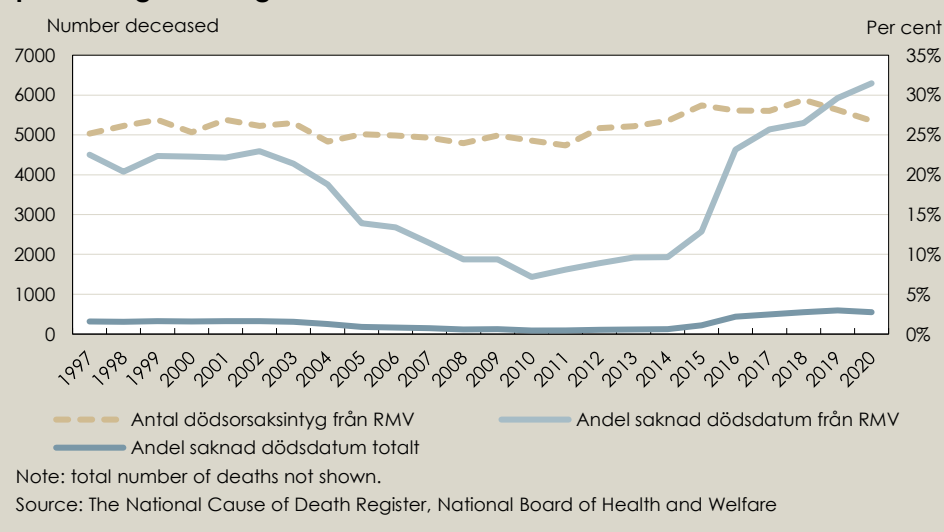
Code	Cause of death
I46.1	Sudden brain death
I46.9	Cardiac arrest, unspecified
I50.9	Unspecified cardiac failure, acute
I95.9	Hypotension, unspecified
I99	Other and unspecified circulatory illness
I96.0	Acute respiratory failure
J96.9	Respiratory failure, unspecified
P28.5	Absence of breathing in newborns
R00-R99. 8	Symptoms, signs of disease and abnormal clinical and laboratory findings not elsewhere classified, excluding R57.2, R60-R65.1 and R65.9

The proportion of causes of death considered insufficiently specified is around 2.5-3 per cent. It has gone up slightly in recent years, as the WHO has included more causes of death among those considered insufficiently specified.

Heart failure may be underlying, but according to the WHO, *acute* unspecified heart failure is insufficiently specified. However, there is currently no list of acute or chronic causes of death in the Register, although this information is available on the cause-of-death certificate. In 2020, a manual review showed that there were 65 deaths with *acute* unspecified heart failure, compared to 2,741 deaths with unspecified heart failure that was not *acute*.

More information on item non-response and under-specified causes of death can be found in the Excel file published together with the official statistics on causes of death in the "About the statistics" tab.⁷

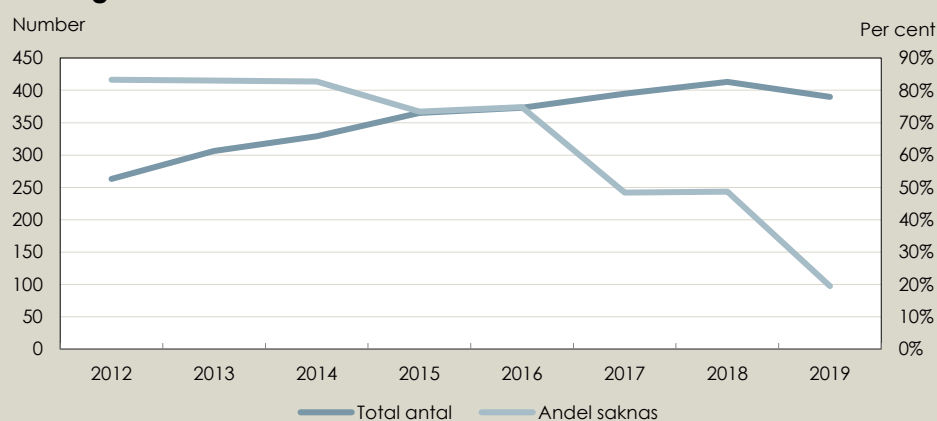
Partial non-response, where some observation variables are unknown, occurs in DORS. This includes missing dates of death, which happens to a greater extent for cause-of-death investigations that come from the National Board of Forensic Medicine (RMV) and include drug and pharmaceutical poisoning (Figure 3).

Figure 3. Number of cause-of-death certificates from RMV and the percentage missing information on date of death from RMV vs.DORS

⁷ <https://www.socialstyrelsen.se/statistik-och-data/statistik/alla-statistikamnen/dodsorsaker/>

Reporting variables for deceased persons who are not registered in the population register, such as gender, are also missing to a greater extent in the Register (Figure 4). However, these are small groups compared to the total amount of data in the National Cause of Death Register.

Figure 4. Not registered: Total number deceased and percentage missing information about sex



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

Since 2015, the municipality where the death occurred is also collected. As the information is based on a free-text field on the certificate that is not always used properly, there is partial non-response. Especially for the year 2015, where 65% are missing a value. However, partial non-response in this case has improved in recent years (6.2% in 2020). Of all deaths that have a value for the municipality where the death occurred, almost 80% are equal to the municipality of registration.

K2.2.4 Data processing

Follow-up questions are asked in some situations where the cause-of-death certificate is unclear or vague. Extent has varied over the years. Before 2010, follow-up questions were asked for deaths up to 75-80 years of age. In 2010 and 2011, there was a strong focus on increasing the timeliness of the Register, and follow-up questions were asked only when the mail was opened. After that, follow-up questions for deaths up to age 65 were restricted until 2021. From 2022 onwards, more extensive follow-up questions will be posed for unclear or vague cause-of-death certificates for deceased persons up to 70 years of age.

Generally, the following cause-of-death certificates prompt a follow-up question:

- Unspecified tumours
- Unspecified terminal cause of death only
- Heart failure or pneumonia as underlying cause of death with no pre-existing disease or condition
- Unclear abbreviations or sequences
- Information suspected missing from the cause-of-death certificate

For deaths that, after about 1.5-2 months, do not have a cause-of-death certificate, a reminder for a cause-of-death certificate is sent to the responsible doctor. Some deaths require a forensic investigation to determine the cause of death, and are referred to the RMV for an autopsy. The responsible doctor is then a specialist doctor at the RMV.

When producing the annual stock, all deaths are taken from the case management system, and demographic variables are ordered from Statistics Sweden. Country of birth, marital status, region, municipality, etc.

The death flow from SCB is also used to detect additional deaths. These amounted to 15 deaths upon correction in 2019.

K2.2.5 Modelling assumptions

Not applicable.

K2.3 Provisional register compared to final register

In 2020, a provisional six-month stock was produced for the first half of 2020. The difference with the final register is that some quality checks, reminders and follow-up questions were not carried out, and the lead time to publication was shorter. One consequence is that the proportion without a cause-of-death certificate is a few per cent greater in the provisional population than in the final register (Table 2). Some specific causes of death, such as deaths requiring a forensic investigation, are not found as much as in the final stock. Provisional six-month stocks (HX) were produced for 2020 H1 and H2, and for 2021 H1, as there was a strong need for cause-of-death statistics. The National Board of Health and Welfare is exploring ways to meet future needs for provisional cause-of-death statistics.

Table 2. Comparison of the first six months (H1) of the final stock with provisional statistics

Year	Number of deaths	Number without cause-of-death certificate	Proportion without cause-of-death certificate (%)	Number of insufficiently specified causes of death*	Proportion of insufficiently specified causes of death *(%)
2019 H1 Final	45,068	337	0.7	1,401	3.1
2020 H1 Provisional	51,534	1,259	2.4	1,248	2.4
2020 Final	51,627	283	0.5	1,321	2.6

K3 Timeliness and punctuality

K3.1 Preparation time

After the pandemic year 2020, the production time for DORS is approximately six months. Before the pandemic, the production time was approximately nine months.

K3.2 Frequency

The Register is made available around mid-year each year. In recent years, this has been done before the summer, but previously the publication was around September each year.

K3.3 Punctuality

Availability has been punctual, except for delays that occurred in 2017 when the National Board of Health and Welfare took over the digitalisation of paper certificates from a subcontractor. The publication of 2017 was delayed by several months.

K4 Accessibility and clarity

K4.1 Access to the register

DORS data may be disclosed for research and statistical purposes. Each request to the National Board of Health and Welfare for disclosure is subject to a confidentiality assessment. The National Board of Health and Welfare's statistical registers are subject to statistical confidentiality according to Chapter 24, Section 8 of the Public Access to Information and Secrecy Act (2009:400).

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

Information about the register 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.⁸

K4.3 Documentation

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

K5 Comparability and interoperability

K5.1 Comparability over time

The Swedish cause-of-death statistics are among the oldest in the world. In 1951, Sweden adopted the international classification of causes of death. The National Board of Health and Welfare follows the WHO's international coding instructions to determine the underlying cause of death. This means that changes in instructions may lead to changes in the statistics over time. More detailed information on how ICD versions were used in Sweden is available in previous cause-of-death publications. Some of the main changes are summarised in Table 3.

⁸ <https://www.socialstyrelsen.se/statistik-och-data/statistik/publiceringskalender-for-statistik>

Table 3. Some of the main changes to the National Cause of Death Register

Period	Description
1952	Start of the register, deaths among persons registered in Sweden, ICD-6
1958	ICD-7 introduced
1969	ICD-8 introduced
1987	ICD-9 introduced
1991	Legislation amended to separate death certificates and the cause-of-death certificates into two forms, leading to non-response of cause-of-death certificates
1994	The National Board of Health and Welfare assumes responsibility for cause-of-death statistics. However, Statistics Sweden continued to produce statistics on behalf of the National Board of Health and Welfare until 2003
1997	ICD-10, and the possibility to register up to 48 different causes of death (the previous register, 1987-1996, contains a maximum of 12 causes of death)
2003-2004	Change in the rules for selecting the underlying cause of death
2004	New cause-of-death certificate (four lines instead of three in the causal chain)
2010	Highest non-response rate combined with accelerated production of the Register
2011-2012	The change in acute/chronic illness on the certificate leading to an increase in unspecified conditions
2012	Deceased persons not registered in Sweden are included in the Register
2015	New cause-of-death certificate (Part II of the certificate became eight lines instead of a larger free-text field, and new acute/chronic tick boxes), unspecified conditions reduced
2019	Substance module published (substances available from 2012)
2019	Additional causes of death are classified as unspecified by the WHO

The National Board of Health and Welfare has previously published a report on the history, production methods and reliability of the National Cause of Death Register, which is available online.⁹

K5.2 Interoperability with other registers

DORS contains the item personal ID number, and thus it is possible to merge¹⁰ causes of death with other data. For example, it is possible to get an idea of the causes of death in relation to education level, which is published in the official statistics.

The National Cause of Death Register uses the international ICD-10 classification. When merging data from the National Cause of Death Register with, for example, the National Patient Register, where ICD-10-SE is used, this means that the National Patient Register may contain national specialisation codes for specific diseases or conditions (the last position in such cases is a letter position in ICD-10-SE) where it is not possible to register at the same level of detail in DORS.

⁹ National Board of Health and Welfare. (2010) *Dödsorsaksstatistik. Historik, produktionsmetoder och tillförlitlighet*. Item no. 2010-4-33

¹⁰ Merging involves linking the data in two or more different registers containing different types of data.

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 Regulation 2016/679¹¹ 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) (*Lagen om den officiella statistiken*), the Ordinance regarding official statistics (2001:100) (*Förordningen om den officiella statistiken*) as well as the Act on the health data register (*Lagen om hälsodataregister*) (1998:543), aka the Health Data Register Act, apply to the processing of personal data.

U2 Retention and data erasure

The National Cause of Death Register is a register where personal data must be exempt from data erasure. The Register is covered by the Swedish National Archives' Regulations regarding exemptions from data erasure and data erasure at the National Board of Health and Welfare (RA-MS 2020:22) (*Föreskrifter om undantag från gallring och gallring hos Socialstyrelsen*). Primary data, i.e., the basis for the register, may be erased five years after the basis has been received by the public agency. However, the National Board of Health and Welfare's enforcement decision¹² of RA-MS 2020:22 states that primary data for the DORS must be preserved.

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.

U3 Obligation to give information

The obligation to provide cause-of-death certificate data to the National Board of Health and Welfare exists according to the Funeral Act (1990:1144) and the Funeral Ordinance (1990:1147)

¹¹ 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).

¹² Decision registered with the National Board of Health and Welfare under number 1.3-26785/2020.

U4 International reporting

According to Article 9(1) of the Regulation on Community statistics on public health and health, etc.¹³, implementing measures are needed to specify the data and metadata to be provided on causes of death covered by Annex III to that Regulation and to define the reference periods and intervals for this information provision.

Such implementing measures are laid down in the Commission Regulation on statistics on causes of death¹⁴ which regulates the transmission of data to the Commission (Eurostat).

The Commission (Eurostat) thus regularly collects statistical data on public health and health and safety at work from the Member States who provide these data on a voluntary basis. In the field of public health statistics, development and implementation is managed and organised through a partnership between the Commission (Eurostat) and the Member States.

Article 3 of the Commission Regulation states that Member States shall transmit to the Commission (Eurostat) the list of variables defined in the Annex to the Regulation.

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.

U6 Contact details

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

Unit: Statistik 2

E-mail: dorcant@socialstyrelsen.se

Telephone: 075-247 30 00

Version history

Version	Change	Date
1.0	The document is new	05/05/2022

¹³ Regulation (EC) No 1338/2008 of the European Parliament and of the Council of 16 December 2008 on Community statistics on public health and health and safety at work

¹⁴ Commission Regulation (EU) No 328/2011 of 5 April 2011 implementing Regulation (EC) No 1338/2008 of the European Parliament and of the Council on Community statistics on public health and health and safety at work, as regards statistics on causes of death See also recital 2 of the Regulation.