

NordForsk PhD course in Register-Based Epidemiology

Cause of death registers

Introduction

All-cause mortality is available through the civil registration systems

An important marker of public health, e.g. life-expectancy

Cause-specific mortality statistics is a valuable source for the identification of risk factors for poor public health

In the Nordic country longstanding national registration of causes of death is available and is essential for much research

Death certificates

Sweden: The decision to document cause of death statistics was made in the Swedish parliament in 1749

All causes of death included in statistics since 1911

Denmark: Since 1871, it has been mandatory by law to complete a death certificate in any case of death occurring in Denmark

Since 1983, the statistics include deaths among Greenlanders and Faroese living in Denmark and dying in Denmark, Greenland, or the Faroe Islands

Denmark

Data from the death certificates are completed for all persons dying in Denmark

Since 1875 legal requirement

Electronic data available since 1970

Information on

- Causes of death: 1 underlying and up to 3 additional causes
- Mode of death
- Date of death
- Place of death
- Municipality

ICD-10 codes since 1994

Finland

From death certificates supplemented with data from CRS

Information on

- cause of death
- age
- sex
- marital status
- other demographic variables
- circumstances of death
- perinatal, neonatal, and infant mortality

ICD-10 codes since 1996

Iceland

All deaths are reported by physicians through a death certificate

Information on

- cause(s) of death
- date of death
- residency of deceased

ICD-10 codes included since 1996

Norway

All deaths are reported by doctors through a death certificate

All deaths in Norway and all persons living in Norway but dying abroad

Information on

- cause(s) of death
- date of death
- location of death

ICD-10 codes since 1996

Sweden

Contains information on all deaths of Swedish residents – whether the death is in Sweden or abroad

The National Board of Health and Welfare receives death certificates on >99% of all deaths

In some (0.5%) of the deaths, no underlying cause of death is reported to the Board - coded ICD code R99.9

Since 1997, the register is matched with CRS to ensure that all deaths are recorded

Contain information from 1961. Historical information is available 1952–1960

Sweden

Information on

- Date of birth
- Country of birth
- Nationality
- Marital status
- Place of residence
- Date of death
- Place of death
- Underlying cause of death
- Contributing causes of death
 - Maximum 0 from 1952 to 1959
 - Maximum 3 from 1960
 - Maximum 6 from 1961 to 1986
 - Maximum 12 from 1987 to 1996
 - Maximum 48 from 1997 onwards

Cause of death - underlying

Underlying cause of death

The most effective public health strategy to prevent death is to prevent the factor causing death

As such, the underlying cause of death is the most important factor to identify when reporting death statistics

The underlying cause of death is defined in ICD-10 as:

(a) the disease or injury which initiated the train of morbid events leading directly to death, or (b) the circumstances of the accident or violence which produced the fatal injury. However, for some disease or injuries, special rules apply

Cause of death - underlying

The process for identifying the underlying cause of death is complex

The physician is required to separate conditions that contributed to the death from other conditions that did not

Moreover, conditions that directly led to the death must be separated from conditions that contributed to the outcome

Contributing causes of death

No priority order

Cause of Death Registers

Direct cause of death (disease or condition directly leading to death)

Due to (chain of events, if applicable)

Due to (underlying cause)

Other significant conditions contributing to death

Cause of Death Registers 1

Direct cause of death (disease or condition directly leading to death)

- Pneumonia

Due to (chain of events, if applicable)

- Tetraplegia

Due to (underlying cause)

- Stroke

Other significant conditions contributing to death

- Diabetes

In this situation **stroke** is underlying cause of death, since it is the disease or injury which initiated the train of morbid events leading directly to death. **Diabetes** is a contributing cause of death but was not in the direct train of events leading to the death

Cause of Death Registers 2

Direct cause of death (disease or condition directly leading to death)

- Hanging

Due to (chain of events, if applicable)

- Depression

Due to (underlying cause)

- Gastric cancer

Other significant conditions contributing to death

In this situation **hanging** is underlying cause of death because there is a special rule that suicide is not considered due to any other condition

Cause of Death Registers

Strengths

Complete data (for decades/centuries)

Comparable data with other countries

Linkage via PIN

Limitations

Validity depends on underlying cause (high for cancer, low for COPD)

Mortality changes for diseases (e.g., HIV/AIDS)

Procedures may change over time (coding COPD instead of emphysema)

Low autopsy rates

Low number of autopsies

Denmark: 10% of deaths at present compared to 75% in the 1970s. Low even in sudden unexpected death occurring outside hospitals

Sweden: 46% of deceased women and 53% of deceased men were autopsied in 1976, compared to 7% of deceased women and 15% of deceased men in 2014

Reported cause of death changed in 30% of cases after an autopsy was performed

50% of cases where the underlying cause of death was coded as IHD, there was no basis for this diagnosis

This does not necessarily imply lower data quality since there have been great developments in diagnostic practices and procedures

Validation studies

Affected by the quality with which the responsible physician certifies the death

Depends on consistency of diagnostic procedures and care taken in recording the death

Mortality statistics are not regularly validated

May invalidate trend analyses, surveillance of medical treatment, and specific research projects

The quality of the whole Swedish cause of death register has not been checked since an investigation of 1094 deaths in 1995 (Johansson et al. J Clin Epidemiol 2006;59:125-31)

All-cause mortality not influenced by these problems

Completeness and validity

Sweden:

Before 1991 the death certificate was legally required for burial

Since 1997 all notified deaths reported to tax authority have been included in the register

Since 2012 the register is updated with the underlying cause of death if the death certificate is received within 18 months of death notification

Cause of Death Registers

Country	Since	Useful websites
Denmark	1943/1970	https://sundhedsdatastyrelsen.dk/dar
Finland	1936	https://www.stat.fi/meta/til/ksyyt_en.html
Iceland	1911/1971	https://www.static.is/publications/metadata?fileid=19603
Norway	1925/1951	http://hrr.uit.no/hrr/
Sweden	1952/1961	https://www.socialstyrelsen.se/register/dodsorsaksregistret