### **About England and Wales Data on Causes of Death**

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### 1. Death Count Data

#### Source of data

Cause-specific mortality data are made freely and publicly available by the Office for National Statistics in two different repertories, namely the 20<sup>th</sup> Century Mortality Files and the 21<sup>st</sup> Century Mortality Files, both in electronic format (see <u>http://www.ons.gov.uk/ons/datasets-and-tables/index.html</u> to download the original files). The data is provided as death counts aggregated by calendar year, sex, age and detailed ICD codes. The files are most detailed, in terms of the categorization of age and cause of death, starting in 1959, when computerized record keeping was introduced by the ONS for statistical tabulations of mortality. For the prior period, the statistics were transcribed from routine annual publications and are provided in the most detailed format available at the time.

### 2. Information on CoD coding

The very first death certificate introduced in 1837 by the newly established Registrar General already included the cause as one of the required pieces of information. At the time, anyone with some acquaintance with the deceased could declare the cause of death but, by 1874, only registered physicians were legally entitled to provide this information (Devis and Rooney, 1999; Maudsley and Williams, 1996). Two distinct certificates are mostly relevant to the Human Cause-of-death Database (HCD) collection: the Medical Certificate of Cause of Death (Form 66) and the Medical Certificate of Cause of Death of live-born children dying within the first 28 days of life (Form 65). There is also a Certificate of still-birth (Form 34) but the information it provides is of no use to the HCD. All deaths requiring an inquest, in particular violent or suspicious deaths as well as sudden deaths of unknown cause, are to be referred by the medical practitioners to the coroner. Those deaths undergo autopsy and they are certified via a separate form (Form 99 or Form 100 depending on the case). About one quarter of all deaths are thereby certified. Since 1927, the medical certificate of cause of death has been following the formats recommended by the World Health Organization (Devis and Rooney, 1999).

Since 1993, the vast majority of deaths (over 97 % according to Devis and Rooney, 1999) are provided by local registration offices to the ONS in electronic format and the ONS compiled all these data into a single database after adding information relative to the deaths otherwise documented. The computerization of death certificates at the local level has been facilitated by the implementation of an automatic coding system called ACCS (Automated Cause Coding System). The ONS is however planning to replace the ACCS

with a new system, called IRIS, an acronym standing for « Institutional Repository for Information Sharing ». The new system includes the latest updates of the ICD-10 classification. IRIS has been developed by Eurostat under the auspices of the World Health Organization and is derived from a combination of MICAR and ACME, the two electronic systems used by the National Center for Health Statistics in the United States to produce cause-of-death statistics. IRIS has already been implemented in several countries of the European Union.

Death statistics are published in England and Wales by the underlying cause defined as the disease that directly lead to death. The exact definition adopted by the vital statistic system follows international recommendations. It is « (a) the disease or injury which initiated the train of events leading directly to death, or (b) the circumstances of the accident or violence which produced the fatal injury » (World Health Organization, 1975). From 1837 to 1910, a national coding frame of about 200 causes was used to classified deaths in England and Wales but the International Classification of Disease (ICD) was adopted in 1911 by the Registrar General. England and Wales has since implemented its successive revisions up to the 10th one, currently in use. Table 1 presents the period of implementation of each ICD revision in the country.

ICD Revision	Years Covered
2 <sup>nd</sup>	1911-1920
3 <sup>rd</sup>	1921-1930
4 <sup>th</sup>	1931-1939
5 <sup>th</sup>	1940-1949
6 <sup>th</sup>	1950-1957
7 <sup>th</sup>	1958-1967
8 <sup>th</sup>	1968-1978
9 <sup>th</sup>	1979-2000
10 <sup>th</sup>	2001-present

Table 1. Periods of implementation of each ICD revision in England and Wales

Source: constructed from information in Griffiths and Brock, 2003, Appendix 1.

In addition, and as explained in the documentation provided by the ONS with the 20<sup>th</sup> Century Mortality Files, changes in the interpretation of the WHO coding rules by the ONS have at times introduced additional disruptions in the cause-specific death statistics series. For instance, between 1984 and 1993, a change in the rule for selecting the underlying cause had a major impact on recorded trends for a number of diseases:

"There is a large increase in mortality from chronic diseases including dementing illnesses, diabetes and rheumatoid arthritis between 1984 and 1993. This is an arterfact due to changes in the way ICD-9 rules for selecting the underlying cause of death were interpreted in England and Wales. Rule 3 states: "If the condition selected by the general rule or rules 1 or 2 can be considered a direct sequel of another reported condition, whether in Part I or Part II [of the certificate], select this primary condition...". From 1984, this rule was interpreted more broadly than before in England and Wales. When one of a list of terminal conditions would otherwise have been selected as the underlying cause but another major condition was recorded in Part II, rule 3 was to be used to select that major condition as the underlying cause of death. As a result, some deaths for which bronchopneumonia in Part I of the certificate would previously have been coded as the underlying cause of death were coded to a condition mentioned elsewhere in Part I or Part II. This led to an abrupt fall in mortality rates for pneumonia and ten other less common conditions regarded as terminal, and a corresponding apparent rise in mortality from many chronic conditions, including diseases of the nervous system and mental disorders, in which bronchopneumonia is a frequent terminal event. The anomaly was reversed by the introduction of an automated system for codinig the cause of death in 1993: the software incorporates the internationally accepted interpretation of the rules for selecting the underlying cause of death" (Office for National Statistics, nd).

The implementation of revised versions of a given ICD also lead to artefactual disruptions in cause-specific death counts. This is the case for the ICD-10 version introduced by ONS in 2011. In its documentation, ONS warns of the lack of comparability between figures for 2001 to 2010 and figures for 2011 and thereafter.

To our knowledge, the ONS has closely followed recommendations of the WHO for the coding and classification of causes of death with no adaptation to its particular setting. The most severe limitation to the England and Wales mortality files results from the implementation of a new neonatal death certificate in 1986 (Form 65), from which it is not possible to assign an underlying cause of death. The new certificate combines information on the diseases and conditions relative to both the infant and the mother. In the electronic files provided by the ONS, all deaths under 28 days have been assigned to a 'dummy' code starting that year. These deaths are included in HMD category no. 84 ('Unknown and unspecified cause').

Another important limitation of the data is the lack of age detail as death counts are provided in five-year age group and only up to 85+ years.

#### **Data quality**

The total number of deaths (all causes, both sex and all ages) by calendar year in the cause-of-death statistics was compared with the total number of deaths by calendar year in the all-cause HMD input database. Differences are expected between the two sources because in England and Wales, as in most countries, there are some situations which result in the delayed registration of the cause of death. More specifically, deaths considered unexpected, accidental or suspicious are referred to a coroner who may

order a post mortem or carry out a full inquest to ascertain the reasons for the death and rule out foul play. In most countries, the coroner can only register the death once an investigation has concluded as to the exact cause and circumstances of the death. It is not uncommon, at least for a small proportion of all deaths, for such registration delays to extend into several years. Unfortunately, the cause-of-death data available for England and Wales is provided by year of registration without information about the year of occurrence. An analyses performed in 2011 by the United Kingdom Office for National Statistics found that 4.3 percent of all deaths registered in 2011 occurred in the years prior, a third of them attributable to external causes (ONS, 2011).

As noted by Mathers and his colleagues, "Even in countries where causes are assigned by medically qualified staff, there is often substantial use of coding categories for unknown and ill-defined causes" and "the proportion of deaths assigned to the ICD codes for "symptoms, signs, and ill-defined conditions" can be used as one indicator of the quality of coding in the registration system" (Mathers et al., 2005, 172). However, too aggressive a push to classify deaths in well-defined categories when there is truly insufficient information to identify the cause of death accurately is not necessarily a useful strategy.

#### Raw data treatment

While applying quality test one inconsistence was detected. There were few deaths from the disease of Parkinson of at young age (see appendix 2), which we referred to secondary parkinsonism.

Finally, the number of non-UCD (underlined causes of death) were recorded into target cause as shown in appendix 3 since these causes may not be considered as principal cause of death.

### **References:**

- Devis, Tim, and Cleo Rooney. (1999). Death certification and the epidemiologist, *Health Statistics Quarterly* 1, 21-33, Office for National Statistics.
- Griffiths and Anita Borck. (2003). Twentieth Century Mortality Trends in England and Wales, *Health Statistics Quarterly* 18: 5-17, Office for National Statistics.
- Maudsley, G. and E.M.I. Williams. (1996). 'Inaccuracy' in death certification Where are we now?, *Journal of Public Health Medicine*, 18(1): 59-66.
- Office for National Statistics, Impact of Registration Delays on Mortality Statistics, 2011, n.d., 2 pages, accessed at <u>http://www.ons.gov.uk/ons/guide-method/user-guidance/health-and-life-events/impact-of-registration-delays-on-mortality-statistics/impact-of-registration-delays-on-mortality-statistics/impact-of-registration-delays-on-mortality-statistics-article.pdf, on May 27, 2016</u>

Office for National Statistics, Twentieth Century Mortality Files, nd, 10 p.

# Appendixes

# Appendix 1. Deaths

Period	Type of Data	Age Grouping	Comments	RefCode(s) <sup>†</sup>
1950- 2019	Annual number of deaths, by sex, age groups with open interval for ages 85+, and underlying cause of death.			30, 32

<sup>+</sup> The reference code is used in the raw data files (Input Database) to link data with sources.

# Appendix 2. Original and recoded age-specific items

Year	Sex	Original cause	Target cause	d10	d15
2001	1	G20_	G219		1
2013	2	G20_	G219		1
2019	2	G20_	G219	1	

# Appendix 3. Recorded non-UCD codes.

Original cause	Target cause	type
A09_	A099	obsolete
A90_	A979	obsolete
B485	B488	dragger
C80_	C809	obsolete
C832	C839	obsolete
C834	C839	obsolete
C836	C839	obsolete
C843	C849	obsolete
C850	C859	obsolete
C932	C939	obsolete
C941	C947	obsolete
C945	C947	obsolete
C961	C969	obsolete
C97_	C969	non-UCD
D463	D469	obsolete
D752	D759	obsolete
D760	D763	obsolete
F100	X45_	non-UCD
F110	X42_	non-UCD
F140	X42_	non-UCD
F190	X40_	non-UCD
G903	G909	obsolete
1150	1139	non-UCD

1159	1139	non-UCD
1220	1212	non-UCD
1228	1212	non-UCD
1229	1212	non-UCD
1252	1258	non-UCD
148_	1489	obsolete
1848	K649	obsolete
1849	K649	obsolete
К350	K358	obsolete
К351	K358	obsolete
К359	K358	obsolete
K511	K519	obsolete
K581	K580	error
K588	K580	error
K85_	K859	obsolete
L89_	L899	obsolete
M725	M729	obsolete
N180	N189	obsolete
N188	N189	obsolete
097_	0979	obsolete
R179	R17_	error
R95_	R959	obsolete