



ONS death registration data and CPRD primary care data Documentation (November 2024)

Version 2.7

Date: 11 November 2024

Documentation Control Sheet

Over time, it may be necessary to issue amendments or clarifications to parts of this document. This form must be updated whenever changes are made.

Version	Affected Areas Summary of Change	Prepared By	Reviewed By
1.0	Initial	Shivani Padmanabhan	Rachael Williams, Helen Strongman
1.1	Modified	Susan Eaton	Rachael Williams, Shivani Padmanabhan
1.2	Updated for set 10 Modified data dictionary	Rachael Williams, Dan Dedman	Helen Strongman
1.3	Formatted: new branding	Grant Lee	Sophia Amjad
1.4	Updated for set 12	Arlene Gallagher	Jennifer Campbell
1.5	Updated for set 13	Arlene Gallagher	Shivani Padmanabhan
1.6	Updated for set 14	Rebecca Ghosh	Shivani Padmanabhan
1.7	Updated for set 15 Formatted: new branding	Rebecca Ghosh	Arlene Gallagher
1.8	Updated for set 16 Modified to include CPRD Aurum	Arlene Gallagher, Rebecca Ghosh	Rachael Williams
1.9	Modified data dictionary	Dan Dedman	Rebecca Ghosh
2.0	Updated for set 17	Arlene Gallagher	Rachael Williams, Catherine Bromley (Office for Statistics Regulation), Ben Windsor-Shellard (ONS Head of Lifestyle and Risk Factors Analysis), Elaine Tower (ONS Coding Improvements Manager on Health Analysis and Life Events, Public Policy Analysis)
2.1	Updated for set 18	Arlene Gallagher	Daniel Dedman, Susan Hodgson
2.2	Updated for set 19	Rebecca Ghosh	Susan Hodgson
2.3	Updated for set 20	Rachael Williams	Susan Hodgson
2.4	Updated for set 21	Arlene Gallagher	Susan Hodgson
2.5	Updated	Susan Hodgson	
2.6	Updated for set 22	Arlene Gallagher	Rebecca Dliwayo
2.7	Updated for 2024 release	Zainab Khalaf	Jenny Campbell

Summary of Changes

Version 1.1

- Corrected errors in and added information to the description of the death_matchrank variable
- Incorporated information about lags in registration and potential implications for research use
- Incorporated updated details on the ICD-10 version used by ONS
- Corrected errors in the descriptions of variables cause_neonatal1 through cause_neonatal8

Version 1.2

- Updated for set 10
 - Added information on match rank variable
 - Removed outdated information on multiple matches
 - Updated details of linkage coverage period
 - Added match_rank and dod_partial variables to data dictionary table

Version 1.3

- Updated header and footer to new agency branding

Version 1.4

- Updated for set 12 and with further information on:
 - The linkage coverage period
 - The proportion of patients linked by match_rank
 - The change from ICD-9 to ICD-10 as of 2001 and selection of underlying cause of death
 - The change in causal sequencing from January 2011

Version 1.5

- Updated for set 13 with information on the new coverage period

Version 1.6

- Updated for set 14 with information on the new coverage period

Version 1.7

- Updated for set 15 with information on coverage period and addition of date of registration (dor), gen_death_id, and n_patid_death variables
- Updated header and footer with new agency branding

Version 1.8

- Updated for set 16 with information on the new coverage period
- Updated to include CPRD Aurum
- Updated to include the place of death category indicators

Version 1.9

- Updated data dictionary for [pod_category]: change type to CHAR 255
- Updated data dictionary for [nhs_indicator]: add lookup values

Version 2.0

- Updated for set 17 with information on the new coverage period
- Updated information on the timeliness of death registrations
- Added a section on coding discrepancies

Version 2.1

- Updated for set 18 with information on the new coverage period
- Updated footer with new NIHR branding

Version 2.2

- Updated for set 19 with information on the new coverage period
- Updated with information on the impact of the COVID-19 pandemic

Version 2.3

- Updated for set 20 with information on the new coverage period
- Updated information on the impact of the COVID-19 pandemic
- Updated information on the timeliness of death registrations

Version 2.4

- Updated for set 21 with information on the new coverage period
- Added DOIs

Version 2.5

- Updated to revise reference to ISAC

Version 2.6

- Updated for set 22 with information on the new coverage period and DOIs
- Updated information on the impact of the COVID-19 pandemic and relevant references

Version 2.7

- Updated for the 2024 linked data refresh including changes in cause of death variables provided and information on new MPSid Linkage method

• **ONS death registration data linked to CPRD primary care data**

This document provides an overview of the Office for National Statistics (ONS) death registration data, and the available subset that is linked to CPRD GOLD and CPRD Aurum.

Impact of the COVID-19 pandemic

The increase in deaths due to the COVID-19 pandemic is reflected in the CPRD linked ONS death registration data. Caution should be used when including death registration data from the period of the pandemic as the impact on the data is as yet unquantified. ONS report that:

- The median time taken for deaths to be registered in 2020 decreased compared with the previous year during the first wave of the COVID-19 pandemic; this was due in part to a more efficient 'virtual' death registration process and a reduction in coroner-certified deaths (which typically take longer to register) [1].
- The mean number of health conditions mentioned on death certificates involving COVID-19 is greater than on non-COVID-19 death. This may reflect either a higher rate of comorbidities in these deaths, a higher quality of certification, or a combination of the two. Additionally, non-COVID-19 deaths saw an increase in ill-defined causes as the underlying cause of death [1].
- Influenza and pneumonia were mentioned on more death certificates than COVID-19 between January and August 2020, however, COVID-19 was the underlying cause of death in over three times as many deaths. Deaths due to COVID-19 were higher than deaths due to influenza and pneumonia between March and June 2020 [2].
- Fewer deaths from causes not related to the coronavirus were recorded between 8 May and 10 July 2020 than the average for deaths at that time of year. There were 6% fewer non-COVID-19 deaths than average in that time, following the period of 7 March to 1 May 2020, where there were 15% more non-COVID-19 fatalities than expected [3].
- The suicide rate in 2020 was statistically significantly lower than in 2019. This decrease is likely to be driven by two factors; a decrease in male suicides at the start of the coronavirus pandemic, and delays in death registration because of the pandemic [4].

Further details about death certification during emergency periods, such as the COVID-19 pandemic, are available in the ONS guidance for the completion of medical certificates for cause of death [5].

What are death registration data?

The Births and Deaths Registration Act (1836) made it a legal requirement for all deaths to be registered from 1 July 1837. The legal requirement to certify and register all deaths occurring in England and Wales means that death registration data provide the most complete information source for mortality statistics. Official mortality statistics for England and Wales are based on the details collected from death registration data.

The registration of deaths occurring in England and Wales is carried out by the Local Registration Service in partnership with the General Register Office (GRO). Information collected at death registration is recorded on the Registration Online (RON) system by registrars. Most of the information is normally supplied by the informant (usually a close relative of the deceased) while the cause of death is usually obtained from the Medical Certificate of Cause of Death (MCCD) completed by a medical practitioner when the death is certified.

When data are entered into RON, there are validation checks to help ensure the details entered are correct. The registrar will also ask the informant to check that the information entered is correct, before the registration is submitted. Regular receipt and diagnostic tests are performed by ONS resulting in weekly contact with the identified registrars to resolve any issues. Once on the ONS database, data are passed through a series of automatic validation processes which highlight any inconsistencies.

Timeliness of death registrations

According to the Births and Deaths Registration Act (1953), a death should be registered within five days unless it is referred to a coroner for investigation. Deaths considered unexpected, accidental or suspicious will be referred to a coroner who may order a post-mortem or carry out a full inquest to ascertain the reasons for the death. The coroner can only register the death once any investigation is concluded and they are satisfied that the death has been thoroughly investigated with a correctly certified cause of death. The time taken to investigate the circumstances of the death can often result in a death registration exceeding the five-day period [6].

Between 2001 and 2020 there has been a decrease in the timeliness of death registration; in 2020, 75.2% of deaths were registered within seven days of the death, compared with 92.7% in 2001 [7]. While registration delays are commonly only a few days, they can occasionally extend into years. In 2020, most deaths were registered within one month (92.9%) [7]. Those deaths which had delays in recording were not random but differential by age at death and/or cause of death. In 2020, the median delay was longer than 6 months (182 days) for deaths caused by: transport accidents (270 days), accidental poisoning by and exposure to noxious substances (191 days), and exposure to smoke, fire and flames (192 days) [7].

Cause of death coding

Coding for cause of death is carried out according to the World Health Organization (WHO) International Classification of Diseases (ICD-10) and internationally agreed rules, allowing for international comparisons. Where possible, cause of death – including the selection of underlying and secondary causes - is automatically coded using specialist software, with the remaining deaths being manually coded by highly trained coders. ICD-10 was introduced in England and Wales in January 2001. Since then various amendments have been authorised by WHO. Amendments may (for example) correct errors in the software supporting automatic coding, accommodate new codes in response to new conditions, such as the H1N1 virus (swine flu), or incorporate advances in medical knowledge of the relationship between conditions.

Until December 2010, ONS used the Mortality Medical Data System (MMDS) ICD-10 version 2001.2 software provided by the United States National Center for Health Statistics (NCHS) to code cause of death. In January 2011, this was updated to version 2010, which incorporated most of the WHO amendments authorised up to 2009.

On 1 January 2014, ONS changed the software used to code cause of death to a package called IRIS (version 2013). IRIS software version 2013 incorporates all official updates to ICD-10 approved by WHO, which were timetabled for implementation before 2014. The ONS provide further details on cause of death coding in the [ONS User guide to mortality statistics](#) [8].

The accuracy of the automated coding is checked regularly. Cause coding of deaths certified after inquest is performed manually. Completeness checks are conducted to ensure all death registrations have been received. Further checks are also carried out before the annual mortality dataset is finalised.

Impact of coding changes

ICD-10 was introduced in January 2001, replacing ICD-9, which had been in use since 1979 [8]. The Office for National Statistics has carried out a comprehensive study to analyse the changes in mortality statistics that are a result of the change in classification. In ICD-10, the first character of each code is alphabetic rather than numeric. This has enabled the expansion of the number of codes to provide for recently recognised conditions and more detail about common diseases. Some diseases and groups of conditions have been moved between broad groups (ICD chapters), from one to another, to reflect current ideas of aetiology and pathology. These changes mean that data cannot easily be compared across ICD-9 and ICD-10. Some changes in the numbers of deaths attributed to diseases are due to artefacts in the coding system.

In addition to the changes in the coding used there have been several changes to the rules governing selection of the underlying cause of death, reducing the number from 9 to 5. The changes in the application of Rule 3 have had the biggest impact. This rule allows a condition that is reported in either Part I or II of the death certificate to take precedence over the condition selected using the other coding rules if it is obviously a direct consequence of that condition. In ICD-10 the list of conditions affected by Rule 3 is more clearly defined than in ICD-9 and is also broader in scope [8]. The impact of this is to reduce the number of deaths assigned to conditions such as pneumonia and to increase the number of deaths assigned to chronic debilitating diseases. In England and Wales, about 20% of deaths mention pneumonia, so the effect of this rule change is large. Examples of determining sequences and the application of the General Principle and Rules 1, 2 and 3 are available from the WHO [9].

When ICD-10 version 2010 was introduced in January 2011, the ONS conducted a bridge coding study [10]. According to the ONS, the main changes in ICD-10 v2010 were amendments to the modification tables and selection rules used to ascertain a causal sequence and consistently assign underlying cause of death from the conditions recorded on the death certificate.

When IRIS was implemented in January 2014, the ONS conducted an impact assessment. Although 95 % of deaths remained in the same chapter, there were significant increases in the deaths allocated to an underlying cause in some ICD-10 chapters (e.g. the mental and behavioural disorders chapter, which includes dementia) and significant decreases in others (e.g. respiratory disease) [11].

Coding discrepancies

There are a few codes present in the ONS death registration data which may not be found in the ICD-10 Classification. Some codes may be erroneous or are no longer in use (I50.2, J84.2) and others refer to the place of accident in the fourth digit (T58.2 [School, other institution and public administrative area], T71.1 [Residential Institution]). The code U50.9 is used specifically by the ONS to identify deaths involving adjourned inquests. On receipt of the outcome of the inquest, the ONS add a final ICD code relating to the definitive underlying cause. R97 is a code created to identify causes which are synonymous with 'Cause Unknown' and is processed differently to other R99 codes (Other ill-defined and unspecified cause of mortality). This code should not appear as the underlying cause of death.

Accessing death registration data linked to CPRD GOLD and CPRD Aurum

ONS death registration data can only be accessed as part of a data extract linked to CPRD primary care data (CPRD GOLD or CPRD Aurum). Access is provided by CPRD subject to protocol approval.

Not all patients in CPRD GOLD or CPRD Aurum are eligible to be linked to death data, for example, due to the region in which they usually resided (outside England), or the lack of a valid NHS number. Source files (linkage_eligibility.txt) are provided to allow researchers to select the subset of patients who are eligible to have a record in the death registration data.

Linkage coverage period

The death registration data includes all deaths *registered* during the coverage period. The latest release (November 2024) covers the period from 7th January 1993 to 03rd April 2024.

Please note that late registration for some deaths means that the proportion of deaths captured is lower for the last year of the coverage period, and this proportion is likely to differ by age at death and cause of death. This is especially pronounced for the last 1-2 weeks of available death data which shows an under count of the total number of deaths as these data do not capture those where the registration of a death has been delayed (e.g. deaths referred to coroners in England, Wales and Northern Ireland, which cannot be registered until investigations have been concluded, and can result in delays of months or years). For more information please refer to the [ONS User guide to mortality statistics](#) [8], the ONS analysis exploring the [impact of registration delays on mortality statistics](#) [6] and the [associated dataset](#) used for this report [12].

Linkage Method

Linkage of ONS Death Registration Data to CPRD primary care data is carried out by our trusted third-party NHS England. Linkage is done using NHS England's Master Person Service (MPS) which replaces the eight-step deterministic algorithm used previously. The Master Person Service extracts demographic information from the Personal Demographics Service database (PDS) held by NHS England, which has approximately 80 million patient records. CPRD patients are matched to PDS patients on NHS number and date of birth. If patients cannot be matched to the PDS database, then the MPS process attempts to ascertain a match based on date of birth, gender and either a local patient identifier or postcode to records in the MPS record bucket (~6% of linked patients in CPRD GOLD and ~2% of linked patients in CPRD Aurum were matched using this secondary method) Each matched patient is assigned a CPRD specific MPS identifier (CPRD MPSid). A list of matched patients' CPRD MPSid's together with their data is provided to CPRD. Further information on how the Master Person Service works can be found in NHS England's Person ID Handbook https://digital.nhs.uk/services/personal-demographics-service/master-person-service/the-person_id-handbook.

Data structure and formatting

As far as possible, the linked death registration data is supplied "as is" without any modification or cleaning during processing by CPRD. Where CPRD has modified the data, these are detailed below.

Modification of the coded data: All ICD codes have been normalized into a standard format.

ICD-9 codes: the 1st character of an ICD-9 code is either a number, the letter V, or the letter E (External Causes of Injury and Poisoning). ICD-9 codes will appear in the data with:

3 characters (formatted as XXX)

4 characters (formatted as XXX.X or EXXX)

5 characters (formatted as EXXX.X)

ICD-10 codes: the 1st character of an ICD-10 code is always a letter. ICD-10 codes will appear in the data with:

3 characters (formatted as XXX)

4 characters (formatted as XXX.X)

All codes associated with a death dated from January 2001 have been formatted as ICD-10.

Place of Death

In the November 2024 release the place of death variable (pod_cod) contains values that are either numeric or alphabetic. The pod_establishment_type classifies the type of establishment where the death occurred, with the values being numeric. The pod_nhs_establishment variable (nhs_indicator in previous release) has three categories with three categories indicates whether the death occurred within an NHS establishment: 0= elsewhere/at home; 1= NHS establishment; 2 = non-NHS establishment.

DOI

Please cite in any publications using these data:

CPRD GOLD ONS deaths November 2024 - <https://doi.org/10.48329/1kxg-ej54>

CPRD Aurum ONS deaths November 2024 - <https://doi.org/10.48329/ne8z-qg89>

Known issues

Before requesting a data extract, you should familiarise yourself with the contents of the ONS death registration data by reviewing the data dictionary as outlined below. Some fields, which are of great potential interest, are/were not mandatory.

- **Date of death (reg_date_of_death):** There are some reg_date_of_death before the start of data collection (1993-1997) and for a small number of records this field is missing, or only a partial date is provided.
- **Date or registration (reg_date):** This field is complete; users may want to consider including information from the reg_date when the reg_date_of_death is missing.
- **Cause of death:** This field is not always complete.

ONS death registration data: Data dictionary

1. Patient file (death_patient.txt)

<i>Column name</i>	<i>Description</i>	<i>Type</i>	<i>Format</i>
patid	Encrypted unique key given to a patient in CPRD GOLD or CPRD Aurum [primary key]	CHAR	18
pracid	Encrypted unique key given to a practice in CPRD GOLD or CPRD Aurum	INTEGER	5
reg_date	Date of registration of death	DATE	yyyy-mm-dd
reg_date_of_death	Date of death	DATE	yyyy-mm-dd
pod_nhs_establishment	NHS establishment indicator for place of death: 0= elsewhere/at home; 1= NHS establishment; 2 = non-NHS establishment	INTEGER	1
pod_cod	Indicates a category for the place of death	CHAR	20
pod_establishment_type	Establishment type where death occurred	CHAR	6
lcd9_orig_mention_1	Cause of death mention ICD9	CHAR	6
lcd9_orig_mention_2	Cause of death mention ICD9	CHAR	6
lcd9_orig_mention_3	Cause of death mention ICD9	CHAR	6
lcd9_orig_mention_4	Cause of death mention ICD9	CHAR	6
lcd9_orig_mention_5	Cause of death mention ICD9	CHAR	6
lcd9_orig_mention_6	Cause of death mention ICD9	CHAR	6
lcd9_orig_mention_7	Cause of death mention ICD9	CHAR	6

lcd9_orig_mention_8	Cause of death mention ICD9	CHAR	6
lcd9_orig_mention_9	Cause of death mention ICD9	CHAR	6
lcd9_orig_mention_10	Cause of death mention ICD9	CHAR	6
lcd9_orig_mention_11	Cause of death mention ICD9	CHAR	6
lcd9_orig_mention_12	Cause of death mention ICD9	CHAR	6
lcd9_orig_mention_13	Cause of death mention ICD9	CHAR	6
lcd9_orig_mention_14	Cause of death mention ICD9	CHAR	6
lcd9_orig_mention_15	Cause of death mention ICD9	CHAR	6
s_cod_code_1	Cause of death mention ICD10 (non-neonatal deaths only)	CHAR	6
s_cod_code_2	Cause of death mention ICD10 (non-neonatal deaths only)	CHAR	6
s_cod_code_3	Cause of death mention ICD10 (non-neonatal deaths only)	CHAR	6
s_cod_code_4	Cause of death mention ICD10 (non-neonatal deaths only)	CHAR	6
s_cod_code_5	Cause of death mention ICD10 (non-neonatal deaths only)	CHAR	6
s_cod_code_6	Cause of death mention ICD10 (non-neonatal deaths only)	CHAR	6
s_cod_code_7	Cause of death mention ICD10 (non-neonatal deaths only)	CHAR	6
s_cod_code_8	Cause of death mention ICD10 (non-neonatal deaths only)	CHAR	6
s_cod_code_9	Cause of death mention ICD10 (non-neonatal deaths only)	CHAR	6
s_cod_code_10	Cause of death mention ICD10 (non-neonatal deaths only)	CHAR	6
s_cod_code_11	Cause of death mention ICD10 (non-neonatal deaths only)	CHAR	6
s_cod_code_12	Cause of death mention ICD10 (non-neonatal deaths only)	CHAR	6

s_cod_code_13	Cause of death mention ICD10 (non-neonatal deaths only)	CHAR	6
s_cod_code_14	Cause of death mention ICD10 (non-neonatal deaths only)	CHAR	6
s_cod_code_15	Cause of death mention ICD10 (non-neonatal deaths only)	CHAR	6
neo_nate_flag	Flag used to indicate if the COD is neonatal	CHAR	6
s_underlying_code_icd10	Original Underlying code for COD ICD10	CHAR	6
s_underlying_code_icd9	Original Underlying code for COD ICD9	CHAR	6

References

- [1] Office for National Statistics, "Quality of mortality data during the coronavirus pandemic, England and Wales: 2020" [Online]. Available: <https://www.ons.gov.uk/peoplepopulationandcommunity/birthsdeathsandmarriages/deaths/articles/qualityofmortalitydataduringthecoronaviruspandemicenglandandwales/2020>. [Accessed 22-December-2021].
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