

Deaths of care home residents: quality assurance of administrative data

Summary of the administrative data sources and quality assurance undertaken in the production of care home resident deaths data, published in annual, weekly, and ad-hoc releases.

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1. Overview

The purpose of this report is to provide information and assurance about the quality of the data used by the Office for National Statistics (ONS) in its <u>annual</u> and <u>weekly</u> releases of care home resident deaths data. This report has been prepared using the <u>UK Statistics Authority's Administrative Data Quality Assurance (QA) Toolkit</u>. The necessary level of data QA needed depends on the risk of data quality concerns, and level of public interest.

The risk of data quality concerns was judged to be medium. The risk to data quality is mitigated for the following reasons:

- there is a legal requirement to register all deaths that occur in England and Wales, resulting in almost complete population coverage for deaths that occur
- · data are collected and supplied to us on a timely basis
- although there are multiple data suppliers (<u>General Register Office (GRO)</u>, <u>Care Quality Commission (CQC)</u>
 , <u>Care Inspectorate Wales (CIW)</u>), there are formal data sharing agreements where appropriate
- there is regular communication between the ONS, data suppliers, and users
- death registrations data are subjected to a series of validation and quality checks by GRO before we receive it, and after being processed through our system
- we have processes to quality assure the data when it comes in, and quality checks built into our analysis
- there are validation and QA procedures in place for CQC and CIW data

It should be noted that the risk of data quality concerns is increased, and therefore judged to be medium. This is because data may be affected by registration delays caused by referral to a coroner or bank holidays resulting in a backlog of data for weekly publications. The ONS produces annual publications on the Impact of registration delays on mortality statistics. Additionally, death registration data only contains information collected as part of civil registration, and some of this information is based on details provided by the informant (usually a close relative).

The public interest was judged to be high because:

- the mortality rate of care home residents represents an important public health concern
- we have several external users, including other government departments (such as <u>Department of Health</u> and <u>Social Care (DHSC)</u> and <u>Cabinet Office</u>) and devolved bodies (such as <u>Welsh Government</u> and <u>Public Health Wales (PHW)</u>)
- organisations use the data to inform policy decisions and monitor the health of the care home resident population
- local authorities use mortality data to aid planning and resource allocation
- there is interest in mortality statistics from the public and the media

Therefore, according to the UK Statistics Authority's <u>risk/profile matrix</u> (page 9 of the Administrative Data QA toolkit), either enhanced (A2) or comprehensive (A3) assurance should be applied to the deaths of care home residents data. We have chosen to apply enhanced (A2) assurance as the risks in terms of data quality concern are mitigated by several factors, therefore enhanced assurance should be satisfactory for our users.

This report will explore each area of practice in the toolkit (operational context and administrative data collection, communication with data supply partners, QA principles, standards and checks applied by data suppliers, producer's QA investigations, and documentation) and outline steps we have taken to quality assure data from the GRO, CQC and CIW.

Further information on the methodology for mortality statistics is available in our <u>Deaths of care home residents</u>, <u>England and Wales Quality and Methodology Information (QMI)</u>, <u>Mortality statistics in England and Wales QMI</u> and the <u>User guide to mortality statistics</u>.

2. Operational context and administrative data collection

Death registrations data

The registration of deaths is a service carried out by the Local Registration Service in partnership with the <u>General Register Office (GRO)</u>. Most deaths are certified by a medical practitioner, using the Medical Certificate of Cause of Death (MCCD). There are exceptions in an emergency period such as the coronavirus (COVID-19) pandemic, where any doctor can complete the MCCD when it is impractical for the attending doctor to do so. For further details about death certification during emergency periods, see <u>Guidance for doctors completing MCCD in England and Wales</u>.

The nature and amount of training doctors have in death certification varies, although "issuing death certificates" is a competency that newly qualified doctors should be able to demonstrate during training. The Coroners and Justice Act 2009 reformed the process of death certification by introducing a single unified system for burials and cremations and appointing medical examiners to provide an independent scrutiny of the cause of death. Under the Coroners and Justice Act 2009, guidance is given to doctors completing MCCDs in England and Wales by the Department for Health Social Care (DHSC) and agreed by the Office for National Statistics (ONS), GRO and National Medical Examiner. Coroners certify about a quarter of all deaths. Training for coroners is organised through the Ministry of Justice. The process of referral to a coroner and how referred deaths are dealt with varies between coroners' areas. See Section 13: Registration of deaths in our User guide to mortality statistics for more information about completing MCCDs.

The MCCD is taken to a registrar by an informant, usually a near relative of the deceased, within five days of the date of death, as required by law. Details of the usual residence of the deceased are supplied by the informant to the registrar. Since 1993, the informant can decide what address to give if more than one is applicable. It is possible for relatives to provide information about the deceased to a registrar in a different district from that in which the death occurred (see Section 7 of our User guide to mortality statistics).

Although deaths should be registered within five days, there are circumstances when a MCCD cannot be issued immediately, such as deaths referred to, and sometimes investigated by, a coroner and so registration is consequently delayed. The Impact of registration delays on the mortality statistics bulletin provides further information on the time taken to register deaths in England and Wales. In the case of deaths referred to a coroner, the coroner sends information to the registrar, and this is used instead of the MCCD to register the death. A very small number of deaths (around 0.5%) remain legally uncertified. In some cases, additional information provided on Part B of the coroner's certificate is forwarded to the ONS by the registrar. See Section 6 Section 6 for more information about the role of coroners in death registrations.

The death registration information used in ONS mortality statistics normally comes from either:

- details supplied by the doctor when certifying a death
- details supplied by the informant to the registrar
- details supplied by a coroner to the registrar following investigation
- details derived from information supplied by one of the above three sources

Care Quality Commission data

The <u>Care Quality Commission (CQC)</u> is the independent regulator of health and social care in England. As part of our annual <u>Deaths of care home residents release</u>, we include the number of deaths of care home residents notified to CQC by local authority.

CQC collects data on deaths of care home residents under Care Quality Commission (Registration) Regulation 16. The intention of this regulation is to ensure that CQC is notified of the deaths of people who use services so that where needed, CQC can take follow-up action.

Providers must tell CQC when someone using their services has died if the person died while a regulated activity was being provided or if their death may have been a result of the regulated activity or how it was provided

Notifications about deaths in care homes must be sent to the CQC without delay by either the CQC Provider Portal, or by completing the MS Word form available on CQC's website and returning via email. Questions to be answered on the online portal differ from those on the MS Word form, however this does not affect the data that are supplied to ONS. Notifications are typically provided within four to five days of death, with low levels of reporting at the weekend and high levels on the first working day of the week. All providers must send notifications directly to CQC. If a notification form is insufficiently complete or missing mandatory information, then CQC will contact the provider directly to obtain missing information.

The data provided by CQC are counts of deaths each day of care home residents who died in care homes, by date of notification. More information on the data provided by CQC can be found in our <u>joint transparency</u> <u>statement</u>.

Notification forms ask service providers about the person who died, including their gender, ethnicity, and other protected characteristics. These questions are not mandatory, so CQC may not get full responses from providers. This would render the dataset incomplete.

Information about place of death is collected on the CQC death notification form. Adult Social Care providers notify CQC of a death of those who use their service regardless of where the death occurs.

The following figures from CQC are collected as part of ONS's weekly deaths release:

- the number of deaths involving COVID-19 in care homes, by date of notification to CQC, in England
- the number of deaths involving COVID-19 in care homes, by date of notification to CQC, by local authority in England
- the number of deaths in care homes, by date of notification to CQC, by local authority in England
- the number of total deaths and deaths involving COVID-19 in care home residents by place of death, per week, in England

Care Inspectorate Wales data

In Wales, the Welsh Government <u>publishes the number of deaths of registered adult care home residents notified</u> to the Care Inspectorate Wales (CIW), based on statutory notifications by care home providers to CIW. These data are included in our <u>annual publication</u> on care home resident deaths.

CIW collects data on deaths of care home residents under <u>The Regulated Services (Service Providers and Responsible Individuals) (Wales) Regulations 2017</u>. The intention of this regulation is to ensure CIW is notified of the deaths of people who use services so that, where needed, CIW can take follow-up action.

Data are collected daily through an <u>online form</u> developed and maintained by CIW. The data are validated against previous returns, with any significant changes queried. Data include all notifications up to midnight each day and covers residents of adult care homes. CIW are also beginning to capture some other characteristics on their death notification form such as age, gender, and disability status.

Notifications about deaths must be sent to CIW without delay. Notifications are typically provided within two to three days of death, with low levels of reporting at the weekend and high levels on the first working day of the week. All providers must send their notifications directly to CIW and must use CIW's secure online portal to make notifications under this regulation. On receipt of the notification, the information is automatically recorded in CIW's internal systems and made available to their inspectors.

Adult Social Care providers who notify CIW of a death advise of deaths of those who use their service regardless of where the death occurs. The online notification form asks providers about place of death.

3. Communication with data supply partners

Death registrations

There is a Service Level Agreement (SLA) in place between Office for National Statistics (ONS) and the <u>General Register Office (GRO)</u>, which sets out what death registration data are to be shared with ONS by the GRO, the legal basis for sharing these data, and when and how often it is to be shared. There is a full data flow process in the SLA which includes the data transfer process. The SLA also covers data security provisions, and procedures for monitoring data quality, resolving issues, and implementing any operational changes. The SLA also includes procedures in case there is a need for modification in the future, such as a new piece of legislation. There are quarterly management meetings between the ONS and GRO, where issues affecting the production of mortality statistics for England and Wales are discussed, including the SLA and data quality.

Feedback on death statistics is welcomed. On all publications related to care home resident deaths, the social care team request that users provide any feedback to health.data@ons.gov.uk.

Care Quality Commission data

There is a Data Sharing Agreement (DSA) for non-disclosive data in place between the <u>Care Quality Commission</u> (<u>CQC</u>) and ONS, for the sharing of annual deaths data. The DSA covers what data are to be shared and how often, the security measures in place and the retention and disposal policy for the data. We maintain regular email contact with CQC and discuss any quality issues related to the data prior to our annual publication.

Secure file transfer systems are used to send and receive death notification data between CQC and ONS. Once received data are held in a secure, password protected area with role-based access. Only anonymised data are shared between CQC and ONS in the format for publication. ONS share publications with CQC for quality assurance purposes prior to release via a secure file transfer system.

Care Inspectorate Wales data

As data from the <u>Care Inspectorate Wales (CIW)</u> are obtained directly from the Welsh Government's <u>StatsWales website</u>, there is no formal DSA in place with CIW. However, we maintain regular email contact with CIW and discuss any quality issues related to notifications data prior to our annual publication.

Secure file transfer systems are used to send and receive death notification data between CIW and ONS. Once received this data is held in a secure, password protected area with role-based access. Only anonymised data are shared between CIW and ONS in the format for publication. ONS share publications with CIW for quality assurance purposes prior to release via a secure file transfer system.

4. Quality Assurance principles, standards and checks applied by data suppliers

Death registrations data

Checks are made on death registration details at various times by registrars, superintendent registrars and account managers from <u>General Registration Office (GRO)</u>. When someone attends to register a death, the registrar is instructed to make several checks, such as that a medical certificate (or coroner's document) is presented. The registrar then carries out the registration and reviews the recorded detail with the informant before the register page is signed by the informant and registrar. Superintendent registrars carry out quarterly checks of registered deaths, and account managers visit registration districts periodically and perform checks of the registration process.

Data items other than cause of death depend largely on information from the informant. For deaths certified after inquest, police officers or other witnesses may supply this information, which cannot be checked by the registrar. For some items of information, such as occupation, there may be no absolute way of checking accuracy. For others, validity (age, date of birth) or "reasonableness" (age, cause of death) may be checked. Some details, such as date of birth, can be verified later with records held at health service data sources.

Before submitting a death registration through the Registration Online (RON) system, the registrar will verify that all information provided has been entered accurately. There are some automatic validation checks within RON to help with this process. Information supplied by the informant is generally believed to be correct since knowingly supplying false information may render the informant liable to prosecution for perjury.

More information on the validation checks in RON and the information supplied when a death is registered and certified is available in <u>Section 13</u>: <u>Registering deaths in our User guide to mortality statistics</u>.

Care Quality Commission data

On receipt of notification, the <u>Care Quality Commission's (CQC)</u> National Customer Service Centre staff enter the main fields from the form into internal systems and make the form available to their inspectors. If providers submit a blank form or one that is insufficiently complete, CQC will contact the provider to obtain the essential missing information. If no response is provided to confirm whether the death was because of confirmed or suspected coronavirus (COVID-19), the assumption is that they were non-COVID deaths.

In analysing the deaths notifications data, CQC analysts clean the data, including removing records where there are duplicate notification ID's. Once analysed, checks are undertaken following CQC's standard quality assurance processes. These processes include systems for data review, analytical clearance and organisational sign-off.

Care Inspectorate Wales data

The death notification data from <u>Care Inspectorate Wales (CIW)</u> is a daily return at a local authority level. Care homes are required to notify CIW of the location and cause of death, with data collected via an online form developed and maintained by CIW. The data is validated against previous returns and significant changes are queried. Data are submitted via a CSV file and transferred to a SQL database. Data includes all notifications up to midnight each day.

A previous review by CIW found that some providers had reported duplicate notifications of the same death, either through error or when attempting to provide updates to previous notifications; these duplicates were removed from the published figures and denoted with an '(r)', indicating that the figure has been revised since the last publication. Duplicates may still occur as providers could report multiple notifications of the same death, however, CIW now conduct regular checks to minimise the impact of this on the data. More information on the quality of the CIW data is available on the <u>StatsWales</u> website.

5. Producer's Quality Assurance investigations and documentation

As part of investigations into the quality of the deaths data, we have identified several strengths, risks, and mitigations; refer to <u>Section 1 Introduction</u> for these.

Death registrations data

We receive data on deaths from registry offices electronically through the Registration Online (RON) system daily. Routine and automated checks are carried out on each file and combined data are then loaded onto the deaths database. Regular receipt and diagnostic reports are produced, resulting in weekly contacts with the identified registrars to resolve any problems. Once on the database, the data are passed through a series of validation processes that are carried out automatically with any inconsistencies highlighted.

All deaths accepted onto the database that need routine coding are identified and coded as required by the Life Events Processing Branch. Automated and manual checks of cause of death data are carried out on all records monthly. Once coding of the cause of death is complete, checks are carried out on variables such as date of death, sex, year of birth, marital status, and communal establishments. These checks evolve continuously during exploratory surveillance of data quality, with some of these later incorporated as routine checks.

Coding for cause of death is carried out according to the World Health Organization (WHO) International Classification of Diseases and Related Health Problems, Tenth Edition (ICD-10) and internationally agreed rules. Automated cause coding is used to derive codes for each medical condition on the certificate and to identify the underlying cause. The accuracy of automated coding is checked regularly within data quality check requirements. For a full explanation, see Section 9: Cause of death coding in our User Guide to Mortality Statistics.

A series of checks before and after extraction of data for analysis are then undertaken. The first of these are carried out as a final check of what is held on the deaths database before an annual extract of data is taken. These comprise frequency checks for a range of fields, covering age, sex, underlying cause, and area of residence. Possible incorrect combinations of fields are checked, and any apparent errors or inconsistencies result in checks of individual cases by coders who make amendments as required. Some of these checks are carried out routinely every month.

Further examinations are carried out once the data extract has been taken, including checks like those done before extraction, to ensure that corrections made at that stage were properly carried out. After the annual extract used for mortality analyses has been produced, a further set of frequency counts and two-way tables are prepared to ensure no new errors were introduced. These checks are to ensure that the frequency distributions are both valid and plausible and similar to those for the previous year's data.

We continuously update the validation checks carried out during data processing, based on surveillance of data quality; where quality issues are found, validation checks are added into routine process. Persistent issues in coding cause of death are referred to a medical epidemiologist for advice and highlighted to the authors of the coding software. For further information, see <u>Section 14: Checking and validation of registration data at ONS Titchfield in our User Guide to Mortality Statistics.</u>

During analysis, we keep a log of any errors or issues that were identified and resolved close to publication date and review these periodically to determine procedures that could prevent these in future. Other improvements to data processes are identified through stakeholder engagement, for example the Mortality Reference Group (to identify and solve problems relating to the interpretation and application of ICD-10 to coding of mortality) and the Federal Institute for Drugs and Medical Devices (IRIS) Core Group (to develop the software used to automatically code causes of death). The same methods are used to estimate Age Standardised Mortality Rates for all our mortality releases, to ensure methods are of sufficient quality.

Once data have been received and processed, analytical outputs relating to care home resident deaths are subject to quality assurance prior to publication, by:

- independent dual run of analysis by two individuals
- comparing trends and patterns against previous periods to check for plausibility
- cross-checking figures that should be equal or similar across different analyses
- checking output tables to ensure that there are no human errors during the creation of published tables
- peer review of publications and tables by colleagues not directly involved in the analysis
- collaboration with external experts with detailed topic or policy knowledge

The number of registration days in a reference period can impact mortality statistics. For example, bank holidays can affect the number of registrations within a week or month because registry offices are usually closed. When it is likely that a bank holiday has affected our statistics, we add footnotes to explain this limitation of the analysis. To overcome some of the problems associated with <u>registration delays</u>, we developed a <u>statistical model</u> to estimate the number of deaths likely to have occurred in each week, based on previous experience of the pattern of registration delays, including the effects of bank holidays. We produce annual publications outlining the <u>Impact of registration delays on mortality statistics</u> to provide information on the annual time taken to register deaths, by cause of death, area of usual residence, age, sex, and certification type.

Care Quality Commission data

For our <u>annual publication</u>, we carry out quality checks on the <u>Care Quality Commission (CQC)</u> data:

- · aggregate totals across different tabs to ensure they sum correctly
- compare the annual data with the weekly series
- check numbers are approximately in line with the numbers from our death registrations data (because of differences in data collection, there will not be an exact match)

Care Inspectorate Wales data

For our <u>annual publication</u>, we reproduce the figures published by the Welsh Government on annual deaths of care home residents and ensure that the figures match between our publication and <u>their website</u> and check the numbers are approximately in line with the numbers from our death registrations data (because of differences in data collection, there will not be an exact match).

By applying these measures and continually monitoring the data received and estimates produced we can continue to assess and ensure the quality of the administrative data received. The data governance and quality assurance in place and relationships with data providers mean that the likely degree of risk to the quality of the administrative data is managed.

6. Related links

For quality and methodology information for deaths of care home residents data, see <u>Deaths of care home residents</u>, <u>England and Wales</u>, <u>QMI</u>.

For information on methods, data quality, legislation and procedures relating to mortality statistics, see our <u>User quide to mortality statistics</u> and our <u>Mortality statistics England and Wales QMI</u>.

Care home resident mortality statistics publications can be found on the <u>deaths section</u> of the Office for National Statistics (ONS) website.

For further queries on care home resident mortality statistics published by ONS, to provide feedback or to request further mortality data, contact: health.data@ons.gov.uk.

7. Cite This Article

Office for National Statistics (ONS), released 28 October 2022, ONS website, methodology article, <u>Deaths of care home residents: quality assurance of administrative data</u>