

Unexplained deaths in infancy: England and Wales QMI

Quality and Methodology Information for Unexplained deaths in infancy: England and Wales, detailing the strengths and limitations of the data, methods used and data uses and users.

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Next release: To be announced

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1. Output information

National Statistic: Yes

Frequency: Annual

How compiled: Based on third party data

• Geographic coverage: England and Wales

• Last revised: 8 September 2022

2. About this Quality and Methodology Information report

This quality and methodology report contains information on the quality characteristics of the data (including the European Statistical System five dimensions of quality) as well as the methods used to create it.

The information in this report will help you to:

- understand the strengths and limitations of the data
- learn about existing uses and users of the data
- · reduce the risk of misusing data
- help you to decide suitable uses for the data
- · understand the methods used to create the data

3. Important points

- The Births and Deaths Registration Act (1836) made it a legal requirement for all births and deaths to be registered from 1 July 1837; the data are the most complete data source available for these statistics.
- The registration of births and deaths is a service carried out by the Local Registration Service in partnership with the General Register Office (GRO) in England and Wales.
- Our unexplained deaths in infancy statistics include both sudden infant deaths and deaths for which the cause remained unascertained after a full investigation.
- The statistics are based on deaths of babies aged under one year that occurred in a given year and where the death record was successfully linked to the corresponding birth record.
- The statistics are not directly comparable with those released in <u>Deaths registered in England and Wales</u>, which are based on deaths registered in each calendar year; to find out more, the Office for National Statistics (ONS) <u>blog</u> explains the differences between registration and occurrence-based statistics in more detail.
- Coding for cause of death is carried out according to the World Health Organization (WHO) International Classification of Diseases 10th revision (ICD-10) and internationally agreed rules, allowing for international comparisons.
- We also produce statistics on <u>unexpected deaths in infancy</u>; unexpected deaths in infancy are infant deaths that are certified by a coroner regardless of the cause of death.
- The unexpected death figures include most unexplained infant deaths (as these are almost always certified by a coroner) and other causes that warrant investigation by a coroner.

4. Quality summary

Overview

Our dataset of unexplained deaths in infancy is used to create the annual release <u>Unexplained deaths in infancy in England and Wales</u>. It includes sudden infant deaths and infant deaths where the causes remained unascertained after a full coroner investigation.

The dataset also includes information about parents because the infant death record has been linked to the infant's birth record. This allows the analysis of risk factors such as birthweight, mother's age at birth of child, mother's country of birth, marital status, parity (number of previous children) and the parents' socio-economic classification based on occupation.

Sudden infant deaths are coded to the International Classification of Diseases 10th revision (ICD-10) with "R95", which is sudden infant death syndrome (SIDS). Infant deaths where there was any mention of the terms "sudden infant death", "cot death", "SIDS", "crib death" or similar terms in the death certificate are included.

Unascertained deaths use the ICD-10 code "R99", which is used for other ill-defined and unspecified causes of death. This release includes infant deaths where the only mention on the death certificate was unascertained death.

More detailed information is available in the <u>User guide to child and infant mortality statistics</u>.

Uses and users

There is a lot of interest in the deaths of apparently healthy infants. The findings of this release help identify some of the risk factors for these infant deaths. Notable users of these data include the Lullaby Trust, the Department of Health and Social Care (DHSC) and Welsh Government.

Other users of this output include academics, independent researchers, charities and the media.

5. Quality characteristics of the unexplained deaths in infancy statistics

Relevance

The degree to which statistical outputs meet user needs in terms of content and coverage.

The registration of births and 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 registration in England and Wales is recorded on the Registration Online (RON) system by registrars. Most of the information is normally supplied by the informant (usually a close relative), 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.

More information on births is available in the <u>User guide to birth statistics</u> and more information on deaths is available in the <u>User guide to child and infant mortality statistics</u> and <u>User guide to mortality statistics</u>.

We quality assure births and mortality data for England and Wales (but not Scotland and Northern Ireland). We then publish statistics for England and Wales based on these data. Statistics for Scotland and Northern Ireland are produced by National Records of Scotland (NRS) and Northern Ireland Statistics and Research Agency (NISRA) respectively. Once published, our statistics are freely available on our website.

All births and deaths that occur in England and Wales must be registered in England and Wales. Births and deaths that occur in England and Wales but relate to people whose usual residence is elsewhere are included in total figures for England and Wales but are excluded from any disaggregations by geography, for example, regions. Conversely, our statistics exclude births and deaths of all residents of England and Wales that occur and are registered elsewhere.

The figures in the Unexplained deaths in infancy release represent infant deaths (deaths under one year of age) that occurred in England and Wales in a given year and were linked to their corresponding birth records. These data include infant deaths whose mother's usual residence was outside England and Wales.

In this release, age at death is broken down into three broad categories in line with widely used definitions in infant mortality:

- neonatal under 28 days
- post-neonatal between 28 days and one year
- infant under one year

A further breakdown of the postneonatal period by months is presented in order to highlight the high concentration of unexplained infant deaths in the months soon after birth.

Unexplained deaths in infancy are published by:

- age at death and sex
- month of occurrence
- regional breakdown for England
- birthweight presented as a grouped variable to draw distinction between death rates
- age of mother at the time the child was born
- marital status of the parents as recorded at the birth registration (inside marriage or civil partnership or outside marriage), and registration type (joint or sole registration)
- number of previous children
- <u>National Statistics Socio-economic Classification (NS-SEC)</u> as defined by occupation; for further information on socio-economic classification, refer to Section 7 of the <u>User guide to child and infant</u> <u>mortality statistics</u>
- mother's country of birth

Mother's country of birth is only broken down as inside the UK, as opposed to outside the UK. In previous years, the numbers of sudden infant deaths were broken down by country. However, because of the small numbers in each category, rates are no longer published as the data are not sufficiently robust.

Timeliness and punctuality

Timeliness refers to the lapse of time between publication and the period that the data relate to. Punctuality refers to the gap between planned and actual publication dates.

There is a lag of 18 months between the end of the reference year, and the date at which the dataset for unexplained infant deaths is extracted. This is because the majority of unexplained deaths are certified by a coroner either with or without an inquest and it takes much longer for these deaths to be registered. The time lag means we have captured almost all of the unexplained infant deaths that occurred in the reference year. However, some deaths are still registered even later than 18 months after the end of the reference year. In recent years, this number of very late registrations has been small, with fewer than 10 additional deaths being registered after the current cut-off.

Further information on the impact of registration delays is available.

For more details on related releases, the <u>GOV.UK release calendar</u> provides 12 months' advance notice of release dates. In the unlikely event of a change to the pre-announced release schedule, we will inform the public of the change and the reasons for it, as set out in the <u>Code of Practice for Statistics</u>.

Coherence and comparability

Coherence is the degree to which data that are derived from different sources or methods, but refer to the same topic, are similar. Comparability is the degree to which data can be compared over time and domain, for example, geographic level.

Figures in the <u>Unexplained deaths in infancy tables</u> are based on the year in which the death occurred. Therefore, these figures will not be directly comparable with those released in <u>Deaths registered in England and Wales</u> as they are based on final underlying cause and the year in which the death was registered.

The Office for National Statistics (ONS) is the only provider of statistics on unexplained deaths in infancy for England and Wales. There are secondary users of these statistics who report the figures provided by us. It is difficult to directly compare these statistics with similar statistics from other countries because of differences in methodology.

Figures for sudden infant deaths are available <u>from 1995 onwards</u>. They have been calculated using the same methodology and are therefore comparable.

Figures for unexplained infant deaths, which includes both sudden infant deaths and unascertained deaths, are available from 2004 onwards. The terms "sudden infant death" and "unascertained" are used interchangeably by coroners certifying these deaths and research shows that the characteristics of infants dying of these two causes are very similar. Therefore, since the 2004 data year, we decided to include both groups in any analysis of unexplained infant deaths.

From the 2012 data year, we changed the method used for reporting National Statistics Socio-economic Classification (NS-SEC) for birth statistics. We now use the combined method, which uses the most advantaged NS-SEC of either parent rather than just the father's NS-SEC. These changes were detailed in Proposed changes to birth statistics by Socio-Economic Classification. The impact of switching to the combined approach was assessed in A combined approach to National Statistics Socio-Economic Classification.

The Human Fertilisation and Embryology Act 2008 contained provisions enabling two females in a same-sex couple to register a birth from 1 September 2009 onwards. In addition, the Marriages (Same Sex Couples) Act 2013 enabled same-sex couples to get married in England and Wales from 29 March 2014. The number of births registered to same-sex couples each year are small, therefore:

- births to same-sex couples who are married or in a civil partnership are included with marital births
- births to same-sex couples who are not married or in a civil partnership are included with births outside marriage

The number of births to same-sex couples is footnoted on relevant tables to assist users.

Amendments to the Population (Statistics) Act 1938 mean that, from May 2012, information is now collected at all birth registrations on the total numbers of previous live births and previous stillbirths that the mother has had (not just those with the current or former husband). This has simplified the question asked by registrars and provides improved coverage. A report describing the <u>changes that have occurred to our birth statistics as a result of improvements to the Population (Statistics) Act (PDF, 539KB)</u> is available. It provides background to the changes and provides high-level findings from the data collected in 2012 and 2013.

Accuracy and reliability

The degree of closeness between an estimate and the true value.

Information recorded at birth and death registration in England and Wales passes through a number of processes before becoming usable for analysis. Our <u>User guide to mortality statistics</u> provides additional information on the collection, processing and quality of mortality data for England and Wales. More specific information relating to stillbirths and infant deaths is available in the <u>User guide to child and infant mortality statistics</u>. The <u>User guide to birth statistics</u> provides detailed information on the registration, collection and quality of births data in England and Wales.

The accuracy of information contained in the draft birth entry is the responsibility of the informant(s), usually the mother, or the mother and father where the registration is a joint one outside marriage. Wilfully supplying false information may render the informant(s) liable to prosecution for perjury. Therefore, it is believed that, in general, the information supplied by the informant(s) is correct.

Occasionally, birth information might be missing from an entry. This can occur for a number of reasons including the informant refusing to give information, or not knowing the information. Under the Population Statistics Act 2012, certain confidential information is collected at the registration of a birth. If any of this information was missing, an appropriate value used to be imputed. However, the number of cases of missing data is now so low that imputation was discontinued in March 2018 to make processing more efficient, and methods easier for users to understand given the impact on statistics is negligible. More information on the imputation of missing births data can be found in Section 3.2 of the <u>User guide to birth statistics</u>.

For deaths, other than the cause of death (including a stillbirth), additional information is supplied to the registrar by the informant when the death is registered. For deaths certified after inquest, the coroner, police officers or other witnesses may supply this information, which cannot later be checked by the registrar.

When a birth or death is registered, the registration system provides the opportunity for the registrar to make validation checks, therefore improving the quality of the data. We conduct internal consistency checks to eliminate any errors made in the supply and recording of birth and death records. Checks are more frequent on those records with extreme values for key variables (such as age of mother and father), as these have a greater impact on published statistics. A small number of registrations are raised with the General Register Office (GRO) on a monthly basis for verification.

The underlying data for this release comprise infant deaths that have been successfully linked to their corresponding birth record. Between 2007 and 2019, around 3% of infant deaths could not be linked to a birth record. The main reasons for this are either that a birth record cannot be found, or the birth was registered outside England and Wales. In 2020, 9.5% of infant deaths could not be linked to a birth record. This increase is likely the result of birth registration services being temporarily suspended in 2020 because of the coronavirus (COVID-19) pandemic. Further information on the linkage process is available in Section 7 of our <u>User guide to child and infant mortality statistics</u>.

Output quality trade-offs

Trade-offs are the extent to which different dimensions of quality are balanced against each other.

The lag between the end of the year that the statistics relate to, and when the statistics are published, is at least 18 months. For example, statistics relating to 2018 were published in early September 2020. This is a long delay. However, we feel it is necessary to safeguard the accuracy of the statistics. Currently, there can be long delays before unexplained infant deaths are registered because they are usually referred to a coroner. Therefore, if we published earlier, too many deaths that occurred in the reference year would be missing from the statistics. We will keep this trade-off under review.

Information on occupation of the mother and father is only coded for a 10% sample of births. This has been shown to give a good approximation to the actual data while being cost effective, given that occupation coding can be labour intensive.

Concepts and definitions

Concepts and definitions describe the legislation governing the output and a description of the classifications used in the output.

Cause of death

The term "sudden infant deaths" was first used as a cause of death in the early 1960s and was defined in 1969 as "the sudden unexpected death of any infant or young child which is unexpected by history and in which a thorough post-mortem examination fails to demonstrate an adequate cause of death". This definition was revised in 1989 by the <u>US National Institute of Health</u> to include only infants dying suddenly under one year of age.

Sudden infant death (SID), sudden unexpected death in infancy (SUDI), sudden infant death syndrome (SIDS) or similar terms are identified by the automatic cause coding system used by the Office for National Statistics (ONS) and are all coded to the International Classification of Diseases 10th revision (ICD-10) code "R95".

The term "cot death" is used interchangeably with "sudden infant death" and the former is more widely used among the non-technical users of statistics on SIDS.

Unascertained deaths (ICD-10 code "R99") are those for which the cause remains unknown after investigation. The changes that have been identified in the certification practices surrounding sudden infant deaths and unascertained deaths suggest that the distinction between these two causes of death is becoming blurred. While sudden infant deaths were previously recorded as natural and the term "unascertained deaths" was used for deaths of unknown cause, this no longer appears to be the case.

National Statistics Socio-economic Classification

We publish unexplained deaths in infancy statistics by National Statistics Socio-economic Classification (NS-SEC), which is derived using the <u>Standard Occupational Classification (SOC)</u> and employment status. SOC is revised every 10 years. The coding of employment status also changed in 2001 to be consistent with the 2001 Census and SOC 2000. Since 2001, <u>NS-SEC</u> has categorised the socio-economic classification of people. The NS-SEC classification is not used internationally although it is based on an internationally accepted classification.

Country of birth

A new coding system for country of birth was introduced in 2006 and was used to code mother's and father's country of birth. The <u>National Statistics country classification</u> is based on the International Standard Organisation (ISO) 3166-1 Codes for the Representation of Names of Countries and their Subdivisions, adapted to meet data needs of UK National Statistics' users and producers.

Birthweight

Birthweight categories in our statistics conform to low birthweight definitions set by the World Health Organization (WHO). The lowest category for our published birthweight statistics is under 1,500 grams. Figures are also published for 1,500 to 1,999 grams and 2,000 to 2,499 grams.

The WHO definitions of low birthweights are:

- low birthweight: less than 2,500 grams
- very low birthweight: less than 1,500 grams
- extremely low birthweight: less than 1,000 grams

Registration

Births occurring outside marriage or civil partnership may be registered either jointly or solely. More detail on the different types of birth registration can be found in Section 4.7 of the <u>User guide to births statistics</u>.

The existing legal provisions for the registration of deaths and the processing, reporting and analysis of mortality can be found in Section 16.3 of the <u>User guide to mortality statistics</u>.

Calculation of rates

The calculation of rates used in the Unexplained deaths in infancy tables are outlined in Section 8 of the <u>User guide to child and infant mortality statistics</u>.

Geography

Geographic breakdowns in our unexplained deaths in infancy publication are based on the latest boundaries available. For more information, please see Section 5 of the User guide to mortality statistics.

Accessibility and clarity

Accessibility is the ease with which users are able to access the data, also reflecting the format in which the data are available and the availability of supporting information. Clarity refers to the quality and sufficiency of the release details, illustrations and accompanying advice.

The latest figures on <u>Unexplained deaths in infancy</u> can be accessed free of charge on our website. From 2020, our datasets have been reformatted to meet the <u>Government Statistical Service's (GSS) accessibility guidelines</u>. <u>Our Unexplained deaths in infancy statistical bulletin</u>, which contains context and commentary, accompanies this release.

Our recommended format for accessible content is a combination of HTML webpages for narrative, charts and graphs, with data being provided in usable formats such as CSV and Excel. Our website also offers users the option to download the narrative in PDF format. In some instances, other software may be used, or may be available on request. Available formats for content published on our website but not produced by us, or referenced on our website but stored elsewhere, may vary. For further information, please contact Health.Data@ons.gov.uk.

For information regarding conditions of access to data, please refer to these links:

- terms and conditions (for data on the website)
- accessibility

Special extracts and tabulations of child mortality data for England and Wales are available to order (subject to legal frameworks, disclosure control, resources and our <u>charging policy</u>, where appropriate). Such enquiries should be made to <u>Health.Data@ons.gov.uk</u> or +44 1329 444110. All <u>user requested data</u> will be published onto the website.

Access to unpublished, de-identified data requires the approval of the independent Research Accreditation Panel (RAP) before access to the data can be provided.

6. Methods used to produce the unexplained deaths in infancy data

Since 2004, the Office for National Statistics (ONS) has maintained a database of unexplained infant deaths that includes information collected at birth and death registration of infants. This database is populated once a year by taking an extract from our registration processing system. It is taken late to allow enough time for registration following certification by a coroner. The deaths are linked to their corresponding birth record where possible to obtain information on social and biological factors of the baby and parents that is only collected at birth registration.

Unexplained infant deaths include both sudden and unascertained deaths of babies aged under one year. More information of how sudden infant deaths and unascertained infant deaths can be found in Section 4 of this quality and methodology report.

How we collect, process and analyse the data

For information on administrative sources of data that the ONS uses to produce statistics, please see the Statement of Administrative Sources.

More detailed information on the main processes used in the compilation of mortality and birth statistics, and on the accuracy and quality of the data used, is available in the <u>User guide to mortality statistics</u> and <u>the User guide to birth statistics</u>.

The infant mortality rates are calculated using the number of live births that occurred in the same year as the denominator. More information on rates can be found in our <u>User guide to child and infant mortality statistics</u>.

Rates are not calculated where there are fewer than three deaths in a cell, denoted by [u]. This is ONS practice, as rates based on such low numbers are susceptible to inaccurate interpretation.

Rates which are based on between 3 and 19 deaths are displayed in tables but are denoted [u] as a warning to the user that their reliability as a measure may be affected by the small number of events.

The ONS policy on protecting confidentiality in birth and death statistics is available on our website.

7. Other information

Assessment of user needs and perceptions

The processes for finding out about uses and users, and their views on the statistical products.

User consultations to review infant mortality statistics took place between <u>20 April and 20 July 2017</u> and between <u>5 July and 16 August 2011</u>. Our response to each review is available.

A <u>proposal for changes to birth statistics by socio-economic classification</u> was published on our website in February 2013. No feedback was received so the outlined changes were implemented.

Proposed changes to child mortality statistics were outlined in the <u>Child Mortality Statistics</u>, <u>2011</u> bulletin (published February 2013) and user feedback was requested. Very little feedback was received so the proposed changes were implemented.

User feedback is requested at the bottom of all emails sent by customer service teams within the Health and Life Events team.

We also receive feedback through regular attendance at user group meetings and conferences.

Useful links

- Child mortality (death cohort) tables in England and Wales: statistics on stillbirths, infant deaths and childhood deaths occurring in a given year in England and Wales.
- <u>Infant mortality (birth cohort) tables in England and Wales</u>: statistics on births and infant deaths based on babies born in a calendar year that died before their first birthday linked to their corresponding birth notification and their corresponding death registration.
- Unexplained deaths in infancy: both sudden infant deaths and deaths for which the cause remained unknown or unascertained.
- Unexpected deaths in infancy: annual data on unexpected deaths (certified by a coroner) and infant deaths
 by selected causes in England and Wales.

The <u>Vital statistics in the UK: births, deaths and marriages</u> dataset provides annual infant mortality data for the UK and its constituent countries (based on deaths registered in a year). The <u>dataset</u> released alongside the <u>Child and infant mortality bulletin</u> provides annual infant mortality data for the UK based on death occurrences. For data for UK countries please see <u>the latest infant death statistics for Northern Ireland</u> and <u>the latest infant death statistics for Scotland</u>. Statistics for Scotland and Northern Ireland are based on death registrations rather than occurrences.

Summary data for infant mortality in England and Wales (based on deaths registered in the year), are available in Deaths registered in England and Wales. A geographical breakdown of infant death numbers and rates by local authority and county (based on deaths registered in a year) is available in Deaths registered in England and Wales by area of usual residence.

The <u>Births summary tables</u>, <u>England and Wales</u>, provide the main summary statistics for live births and stillbirths in England and Wales.

More general information on the collection, production and quality of mortality data is available in the <u>User guide</u> to mortality statistics.

8. Cite this QMI

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