

Gestation specific infant mortality in England and Wales QMI

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1. Methodology background

National Statistic	
Survey name	Gestation specific infant mortality in England and Wales
Frequency	Annual
How compiled	Sample based survey
Geographic coverage	England and Wales
Last revised	13 July 2012

2. Overview

- based on our birth and infant death data and birth notifications data provided by the NHS Numbers for babies (NN4B) system
- includes date of birth, sex, whether it is a single or multiple birth and information about the parents
- there is a delay of about 18 months between the publication date and the data coverage period, this allows all births in the reference year to be linked to the infant deaths

Gestation specific infant mortality is based on our birth and infant data, which includes information from the NHS NN4B. This statistical bulletin reports the estimates for births and infant deaths by gestational age and ethnicity. Gestational age is calculated from relevant menstrual data held in the maternal records of the mother. Information on gestational age at birth is important as babies born preterm are at a higher risk of morbidity and mortality in the early years of life.

Births registration data are births that occur and are then registered in England and Wales. Registration within England and Wales is legally required within 42 days of birth. Birth notifications data from the NHS NN4B system includes NHS numbers and records important details not collected at birth registration, including gestational age and ethnicity (specified by the mother). Every birth must be notified to the Regional Director of Public Health within 36 hours of its occurrence.

The Department of Health is one of the main users of these statistics; they are used to inform policy decisions and to monitor infant mortality under a new <u>Public Services Transparency Framework</u>.

3. Executive summary

The Gestation specific infant mortality in England and Wales <u>statistical bulletin</u> is based on birth and infant death data produced by ONS and birth notifications data provided to us by th National Health Service (NHS) Numbers for [Babies (NN4B) system. Summary quality reports for <u>Births</u>, <u>Child mortality statistics</u> and <u>Infant and perinatal mortality by social and biological factors</u> are available on our <u>website</u>.

The <u>statistical bulletin</u> presents statistics on births that occurred in England and Wales in a particular year that have been linked to the NHS birth notifications data. The NN4B electronic system for the notification of each birth allocates NHS numbers and records key birth details that are not routinely collected at birth registration.

This linked births dataset is further linked to death registration records for babies who died before their first birthday. This permits analyses using gestational age and ethnicity, which are important factors in understanding births and infant deaths.

This document contains the following sections:

- Output quality
- About the output
- · How the output is created
- Validation and quality assurance
- · Concepts and definitions
- Other information, relating to quality trade-offs and user needs
- · Sources for further information or advice

4. Output quality

This document provides a range of information that describes the quality of the data and details any points that should be noted when using the output. We have developed <u>Guidelines for measuring statistical quality</u>; these are based upon the six European Statistical System (ESS)

quality dimensions. This document addresses these quality dimensions and other important quality characteristics, which are:

- relevance
- · timeliness and punctuality
- · comparability and coherence
- accuracy
- output quality trade-offs
- assessment of user needs and perceptions
- · accessibility and clarity

More information is provided about these quality dimensions in the sections below.

5. About the output

Relevance

The degree to which statistical outputs meet user's needs.

The existence of large inequalities in infant mortality rates between white and ethnic minority groups in England and Wales is well documented (<u>Gray and others, 2009</u>), but ethnicity data are not routinely collected at the registration of a birth.

This statistical bulletin reports figures for births and infant deaths by gestational age and ethnicity, which would not be possible without the data linkage. We have undertaken this linkage since 2008. Gestational age is calculated from relevant menstrual data held within the maternal records of the mother. Information on gestational age at birth is important as babies born preterm, before 37 completed weeks of gestational age, are at a higher risk of morbidity and mortality in the early years of life. Thus, data on gestational age are needed to monitor trends in preterm birth and to inform the development of programmes aimed at primary and secondary prevention of impairment and disability in childhood (Hilder and others 2007).

The Department of Health (DH) is a key user of child mortality statistics. Aggregate data are used, for example, to inform policy decisions and monitor infant mortality under a new Public Services Transparency Framework (this has replaced the Public Service Agreement system that was in place under the previous government). One of the outcome measures in the NHS Outcome Framework is the proportion of all term babies (<=37 weeks gestation) admitted to neonatal care. The denominator in this rate (the number of term live births) is derived from the Gestation-specific infant mortality report.

The DH business plan (2011 to 2015) includes an impact indicator for the incidence of low birthweight (<2500 grams) of term (37 gestation weeks) live births. These figures are also derived from this dataset.

Timeliness and punctuality

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

There is a delay of approximately 18 months between the publication date and the end of the period to which the data refer. This allows the linkage of all births in the reference year to all infant deaths. Therefore, the infant deaths data from the reference year and the subsequent year must be available to ensure completeness for all infant deaths. For example, the 2009

Gestation specific infant mortality bulletin links all babies who were born in 2009 to the infant deaths data for 2009 and 2010.

The <u>Gestation specific infant mortality statistical bulletin</u> is announced on the <u>UK National Statistics Publication</u>

<u>Hub</u> at least four weeks in advance of publication. For more details on related releases, the <u>UK National Statistics</u>

<u>Publication Hub</u> is available online and provides 12 months' advance notice of release dates. In the unlikely event of a change to the pre- announced release schedule, public attention will be drawn to the change and a full explanation for the change will be provided, as set out in the <u>Code of Practice for Official Statistics</u>.

6. How the output is created

We are responsible for publishing statistics on births and infant mortality in England and Wales. Detailed descriptions for the methods used to compile birth and infant mortality statistics can be found in the relevant standard quality reports: Quality and methodology information for births, Quality and methodology information for child mortality statistics.

Births registration data are births that occur and are then registered in England and Wales. Registration of a birth within England and Wales is legally required within 42 days of its occurrence. As well as details of the birth (date of birth, sex, whether it is a single or multiple birth) additional information is collected about the parents both for the public register and for statistical purposes, such as mother's usual residence and her age at the time of the baby's birth. Information about the father, such as his occupation, is collected if the parents are married or if the father is present when the birth is registered (joint registration). Marital status and registration type is determined from birth registration records.

Birth notifications data from the NHS Numbers for Babies (NN4B) system includes NHS numbers and records key birth details not collected at birth registration, including gestational age and ethnicity. Every birth must be notified to the Regional Director of Public Health within 36 hours of its occurrence. The NN4B system collects ethnicity to assist with organisations' monitoring of their service delivery. While ethnicity is usually self-defined, in this dataset ethnicity is the baby's ethnic group as stated by the mother.

We receive birth notifications data from the NHS for linkage with birth registration records for statistical purposes. Birth registration records are linked to birth notifications records using NHS number as the primary means of linkage. In 2009, 99.4% % of all birth registrations were successfully linked to the birth notifications data using the NHS number. Stillbirths and registration records that had no NHS number are matched probabilistically using indirect identifiers such as date of birth, birthweight, mother's date of birth, and postcode. Details of the linkage process are described elsewhere (Hilder and others, 2007).

This linked births dataset is further linked to death registration data to identify infants who died before their first birthday using the variable that is added to a birth record by ONS to indicate a death. Registration data on all deaths occurring in England and Wales are held by ONS.

7. Validation and quality assurance

Comparability and coherence

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

The Births and Deaths Registration Act (1836) made it a legal requirement for all births to be registered from 1 July 1837. Registration requirements have changed over the years, for example the introduction of the Population Statistics Act (1938, 1960) allowed for more detailed information to be requested from the informant.

We have reported statistics based on NN4B-linked data since 2008 and the mechanism of data linkage has remained the same. Therefore, a comparable time series for England and Wales is available for births occurring from 2005 onwards.

As the established source of birth data, birth registration is considered to include all babies because of the civil uses of the birth and stillbirth certificates issued. The assessment of the births notification data was based on the coverage and consistency of the data relative to the births notification data. Coverage refers to the extent to which data are available for all registrable births. A crude method compares the number of NN4B records with those for registrations. One-to-one record linkage is a powerful test that the two sources contain records for the same individuals. In 2009, 99.4% %of all birth registrations were successfully linked to the birth notifications data using the NHS number. Completeness refers to the extent to which individual data items have non-missing data. Null and dummy values were included with missing values.

In linked data, the values for data items common to both sources can be compared. If the values from sources for a given variable are identical, the data are described as concordant. If they differ, the data are discordant. Measurement of the extent of data consistency can be used to comment on data quality in one source relative to another if the data item was not used for linkage, if there is non-missing data in data items from each source and if there is no doubt about the accuracy of the record linkage. In 2005, there was no discordance in any of the data items common to each source in 83.4% %of all linked records. This was similar to the 83.5% %complete concordance rate for records linked using NHS numbers, but higher than the 74.9 % of records with complete concordance where linkage was achieved using indirect identifiers (Hilder et al. 2007).74.10

Doubt is raised about the accuracy of record linkage if identical values are not seen in the same data items from both sources. The exception is postcode which can change if the mother moves house before she registers the birth. As some recording errors are to be expected in routine data, allowance is made for data discordance in one data item, but there is serious doubt about the linkage if three or more items of data are discordant.

Accuracy

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

Whilst gestational age in completed weeks is recorded for all live births on the NHS Birth Notifications system, it is not available for live births from registration data alone. Prior examination of the quality of NN4B data has shown this variable to be credible and comparable with other UK data sources (Moser and Hilder, 2008). However, there are data quality concerns regarding births recorded as occurring before 22 weeks gestational age. These include inconsistencies in the recording of gestational age and birthweight information. Some of these births are recorded with a birthweight of 2,500g and over. This is clinically implausible as it would be expected that low gestation babies would have very low birth weights. Data from the Canadian Perinatal Surveillance system indicated that singleton births of 22 weeks gestational age have an upper limit for birthweight below 750 grams (Public Health Agency of Canada, 2001). To circumvent this issue, the statistical bulletin separates the births and related deaths of below gestational age into those with plausible birthweights (under 1,000g) and those with implausible birthweights (1,000g and over) for this gestational age. In the 2009 bulletin, there were 68 births and eight deaths that fell into this category.

Data quality concerns also exist regarding the proportion of records with "Not Stated" values as this is an important measure of the usefulness and quality of the data. For instance, individuals may choose not to state their baby's ethnicity. In local areas with a very high proportion of "Not Stated" records this "opting out" may not be the sole reason for incomplete data. The "Not Stated" response category for ethnicity may also indicate non-responses of "Not Known", "Missing" or "Not Asked". In the 2009 NN4B dataset, 6 % of live birth records had ethnicity recorded as "Not Stated" (ONS, 2011). A statistical bulletin exploring the Quality of the ethnicity and gestation age data for local areas for live births and infant deaths was published in September 2011 and is available on our website. The results showed disparities in the completeness of ethnicity and gestational age variables for different local authorities.

The linked infant deaths dataset consists of infant deaths that have been linked to the corresponding birth in a given year. For deaths of infants born in 2009, 99.3 % were successfully linked to their birth records.

8. Concepts and definitions

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

The <u>Gestation specific infant mortality statistical bulletin</u> is published at England and Wales level. Details on the governance of the NN4B dataset can be found on in the Pilot linkage of NHS numbers article available on <u>our website</u>. The summary quality reports for <u>Births</u> and <u>Child mortality statistics</u> also contain details on the legislation and governing the collection of births and deaths data.

Key definitions and terms for births, stillbirths and infant deaths that are defined in this report include:

- Stillbirth born after 24 or more weeks completed gestation and which did not, at any time, breathe or show signs of life
- Early neonatal death deaths under seven days
- Neonatal death deaths under 28 days
- Postneonatal death deaths between 28 days and one year
- Infant death deaths under one year
- Rates neonatal, postneonatal and infant mortality rates are reported as deaths per 1,000 live births
- Gestational age gestational age is calculated from relevant menstrual data held within the maternal
 records of the mother. Gestational age is measured in completed weeks. For gestational age recorded as
 less than 22 weeks, this was considered as valid if there was a plausible birthweight (less than 1,000g); a
 separate category was created for gestational age less than 22 weeks and inconsistent birthweight (1,000g
 or more) which is reported separately.
- Gestational age was also grouped (excluding the less than 22 weeks with inconsistent birthweight group):
- Under 24 weeks
- Preterm: 24 to 26 weeks
- Term: 37 to 41 weeks
- Post-term: 42 weeks or more

Ethnicity: the baby's ethnic group is defined by the mother. Two groupings are used in this report:

Nine groups

- 1. Bangladeshi Asian or Asian British, Bangladeshi
- 2. Indian Asian or Asian British, Indian
- 3. Pakistani Asian or Asian British, Pakistani
- 4. African Black or Black British, African
- 5. Caribbean -- Black or Black British, Caribbean
- 6. White British White, White British
- 7. White Other White, White Irish and any other White background
- 8. All Others All Mixed groups; all 'any other' groups (Asian, Black, other); Chinese
- 9. Not stated

Five groups

- 1. Asian Bangladeshi, Indian, Pakistani and any other Asian background
- 2. Black African, Caribbean and any other Black background
- 3. White White British, White Irish and any other White background
- 4. Mixed, Chinese, Other All Mixed groups; Chinese; any other ethnic group
- 5. Not stated:

9. Other information

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

Checks are carried out quarterly by ONS on the birth registration data in preparation for the release of provisional quarterly figures. These checks pick up any suspect records or information within a record that needs to be queried with the <u>General Registry Office</u> (GRO). These records are then corrected where appropriate.

Any birth records which are still missing mother's age, father's age, marital status, duration of marriage or previous number of children for births within marriage, are imputed. This process means that all records can be published by these variables. Although imputation means that the data are not exact, time is not spent waiting for the information to be corrected and costs are kept to a minimum.

The information on occupation of the father is coded for a 10% sample of births. The 10% sample coding for occupation was found to give a good approximation to the actual data while being cost effective (ONS, 2007). Combining occupation with employment status means that a code for socioeconomic classification (NS-SEC) can be derived. Analysis is currently being carried out to evaluate the use of both parents' NS-SEC for the production of birth and infant mortality statistics by socio-economic classification. This approach was used in a recent analysis of inequalities in fatal childhood accidents and assaults (Siegler and Al- Hamad, 2010).

Assessment of user needs and perceptions

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

An <u>infant mortality user consultation</u> was undertaken in summer 2011 to ensure that our outputs are coherent and continue to meet user requirements; the results were published in November 2011. There was support for the continued publication of birth cohort data for infant deaths.

The Maternity Exchange Information user group and Fertility Management meetings also create an opportunity to connect with both suppliers and users of the data.

10. Sources for further information or advice

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 infant mortality and births by gestational age, ethnicity and birthweight can be accessed free of charge on the Office for National Statistics website. The relevant release contains information relating to the quality of the data and relevant legislation and procedures.

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. For further information please refer to the contact details at the beginning of this document.

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

Terms and conditions (for data on the website)

- Copyright and reuse of published data
- Pre-release access (including conditions of access)
- Access to unpublished data
- Access to microdata via the Virtual Microdata Laboratory
- Accessibility

The NN4B data includes information collected while women are patients in hospital. Individual informed consent is not obtained to process this patient data. We have obtained support under Section 251 of the NHS Act 2006 to process this data. We cannot release disclosive tables or microdata to customers unless they also obtain Section 251 support.

In addition to this Quality and Methodology Information, Basic Quality Information relevant to each release is available in the background notes of the relevant <u>statistical bulletin</u>.

Useful links and background articles

Chow YH, Dattani N (2009) 'Estimating conception statistics using gestational age information from NHS Numbers for Babies data' Health Statistics Quarterly, No 41' av

General Register Office

Moser K (2009) 'Gestation-specific infant mortality by social and biological factors among babies born in England and Wales in 2006' Health Statistics Quarterly, No 42'

Moser K, Dattani N, Leon DA, Stanfield KM (2008) 'Data on births by ethnic group now available for England and Wales' BMJ, Vol 337

Moser K, Hilder L (2008) 'Assessing quality of NHS Numbers for Babies data and providing gestational age statistics' Health Statistics Quarterly, No 37

Moser K, Macfarlane A, Chow YH, Hilder L, Dattani N (2007) 'Introducing new data on gestation-specific infant mortality among babies born in 2005 in England and Wales' Health Statistics Quarterly, No 35'

Moser K, Macfarlane A, Dattani N (2008) 'Survival rates in very preterm babies in England and Wales' Lancet, Vol 371'

Moser K, Stanfield KM, Leon DA (2008) 'Birthweight and gestational age by ethnic group, England and Wales 2005: introducing new data on births' Health Statistics Quarterly, No 39'

Oakley L, Maconochie N, Doyle P, Dattani N, Moser K (2009) 'Multivariate analysis of infant death in England and Wales in 2005-06, with focus on socio-economic status and deprivation' Health Statistics Quarterly, No 42'

Office for National Statistics (2007) 'Preterm births, England and Wales, 2005' Health Statistics Quarterly, No 35'

Office for National Statistics (2011) 'Quality reports for social statistics', available at: www.ons.gov.uk/ons/guide-method/method-quality/quality-information/social-statistics/index.html

11. References

Department of Health (2010) NHS Outcomes Framework <u>www.dh.gov.uk/en/Publicationsandstatistics/Publications</u>/PublicationsPolicyAndGuidance/DH 122944

Department of Health (2010) 'Transparency in outcomes – a www.dh.gov.uk/en/Consultations/Liveconsultations /DH 117583

Gray R, Headley J, Oakley L, Kurinczuk JJ, Brocklehurst P and Hollowell J (2009) 'Inequalities in infant mortality project briefing paper 3. Towards an understanding of variations in infant mortality rates between different ethnic groups'. Oxford: National Perinatal Epidemiology Unit. www.npeu.ox.ac.uk/files/downloads/infant-mortality/Infant-Mortality-Briefing-Paper-3.pdf

Hilder L, Moser K, Dattani N, Macfarlane A (2007) 'Pilot linkage of NHS Numbers for Babies data with birth registrations' Health Statistics Quarterly, No 33 www.ons.gov.uk/ons/rel/hsg/health-statistics-quarterly/no--33--spring-2007/health-statistics-quarterly.pdf

Messer J (2011) 'An analysis of the socio-demographic characteristics of sole registered births and infant deaths', Health Statistics Quarterly, No 50 https://www.ons.gov.uk/ons/rel/hsq/health-statistics-quarterly/no--50--summer-2011/an-analysis-of-the-socio-demographic-characteristics-of-sole-registered-births-and-infant-deaths.pdf

Messer J (2011) 'Quality of ethnicity and gestation data subnationally for births and infant deaths in England and Wales, 2005-2008' www.ons.gov.uk/ons/rel/child-health/quality-of-ethnicity-and-gestation-data-subnationally-for-births-and-infant-deaths-in-england-and-wales/2005-08/stb.html

Office for National Statistics (2007) 'Birth Statistics, England and Wales' www.ons.gov.uk/ons/rel/vsob1/birth-statistics-series-fm1.pdf

Office for National Statistics (2011) 'Review of infant mortality statistics: user consultation' www.ons.gov.uk/ons/about-ons/consultations/2011/review-of-infant-mortality-statistics/index.html

Public Health Agency of Canada (2001) 'Birthweight for Gestational Age data' Canada Perinatal Surveillance System

www.phac-aspc.gc.ca/rhs-ssg/bwga-pnag/index- eng.php

Siegler V and Al-Hamad A (2010) 'Social inequalities in fatal childhood accidents and assaults: England and Wales,2001-03'. Health Statistics Quarterly, No 48 http://www.ons.gov.uk/ons/rel/hsq/health-statistics-quarterly/no--48--winter-2010/index.html