

Evaluation of the availability and quality of data required to model intrapartum mortality by planned place of birth

Addendum to the Birthplace in England research programme final report

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Published April 2014

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This report should be referenced as follows:

Hollowell J, Macfarlane A. Evaluation of the availability and quality of data required to model intrapartum mortality by planned place of birth. Addendum to the Birthplace in England research programme final report. NIHR Service Delivery and Organisation programme; 2014.

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Glossary of terms/abbreviations

AMU	Alongside Midwifery Unit
CEMACH	Confidential Enquiry into Maternal and Child Health
CMACE	Centre for Maternal and Child Enquiries
FMU	Freestanding Midwifery Unit
HES	Hospital Episode Statistics
NHS	National Health Service
NICE	National Institute for Health and Clinical Excellence
NIHR	National Institute for Health Research
NPEU	National Perinatal Epidemiology Unit
NPSA	National Patient Safety Agency
ONS	Office for National Statistics
PPOB	Planned place of birth

Acknowledgements

This report was prepared on behalf of the Birthplace in England Collaborative Group which includes the wider group of co-investigators, advisors, researcher, project staff and coordinating midwives who contributed to the research programme, Members are listed in Part 1 of the final report.

The evaluation described in this addendum was conducted by a working group. Membership of the group was: Jennifer Hollowell, Alison Macfarlane, David Puddicombe and Nirupa Dattani.

Report

Introduction and report overview

A study of intrapartum related mortality was planned as part of the Birthplace in England research Programme. The intention was to model intrapartum mortality by planned place of birth using data from a number of different sources, including routine birth statistics and data from the Confidential Enquiry into Stillbirths and Deaths in Infancy.

This report describes the analyses conducted to assess the availability and validity of the key routine data sources required to estimate intrapartum related mortality by planned place of birth at the onset of labour. This assessment identified a number of data issues affecting the feasibility of generating valid intrapartum mortality estimates by planned place of birth. For the reasons summarised on page 18 below, a decision was therefore taken not to proceed with the study.

Background

Intrapartum related perinatal mortality is rare in 'low risk' women. Because of this, the Birthplace national prospective cohort study used a composite primary outcome measure that captured both intrapartum mortality and intrapartum related neonatal morbidity. Use of this composite outcome gave the study more statistical power to detect differences in safety between planned places of birth, but a limitation is that use of a composite outcome may conceal important differences in outcomes between settings, for example more severe outcomes in one setting.

Study aim

The aim of the Birthplace national intrapartum mortality study was to estimate intrapartum related perinatal mortality (intrapartum stillbirths and intrapartum related early neonatal deaths) by planned place of birth at the onset of labour in women considered to be at 'low risk' of complications prior to the onset of labour.

Overview of data sources and methods

The study was challenging as planned place of birth at the onset of labour is not routinely recorded in NHS information systems, as it is not included in the NHS Data Dictionary. The study was therefore planned as a modelling study. The

intention was to use the CEMACH ^a (subsequently CMACE) perinatal death notification system to provide data on the numbers of intrapartum stillbirths and early neonatal deaths for births to 'low risk' women in England classified by intended place of delivery at the onset of labour. Routinely collected birth registration and hospital discharge data were to be used in combination with data from other sources and published analyses to estimate the number of eligible 'low risk' births which were planned to occur in each setting. It was originally intended to base the analysis on data for the years 2006-2007 but for the reasons explained below the proposed analysis period was changed to 2008 -2009. The data sources and an overview of the estimates and parameters to be derived from each of these data sources are listed in table 1.

Table 1 Data sources for intrapartum mortality model

Denominator data (planned births by setting)	
ONS birth registration data	Singleton, term births by actual place of birth (home, FMU, AMU, OU)
The Birthplace in England national cohort study	1. Intrapartum transfer rates prior to birth for planned home, FMU and AMU births 2. The proportion of term, singleton OU births that are 'low risk'
Hospital episode statistics (HES)	The proportion of term, singleton OU births delivered by elective caesarean section
Published reports/survey data	Unplanned births at home as a proportion of all births
Numerator data (intrapartum stillbirths and early neonatal deaths by planned place of birth)	

^a The Confidential Enquiry into Maternal and Child Health (CEMACH) became the Centre for Maternal and Child Enquiries (CMACE) in 2009.

CEMACH/CMACE perinatal death notifications for England	Intrapartum stillbirths and neonatal deaths by planned place of birth in women at low risk of complications
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Purpose of this report

This brief report describes the work conducted to assess the availability and quality of the ONS, HES and CEMACH/CMACE data required for the analysis.

Denominator data

The proposed model required the following data derived from routinely collected data on births:

- The numbers of term, singleton births registered in England, by actual birth setting, by year of occurrence
- The number of term, singleton births delivered by caesarean section in NHS obstetric units in England as a proportion of all term, singleton births in NHS obstetric units in England, by year of occurrence

Birth registration data by birth setting

We obtained special tabulations of all live birth registrations and all registrations of singleton live births at gestational ages of 37 or more weeks ('eligible' births) in England by actual birth setting ('place of confinement') from ONS for the years 2008 and 2009. Only the location of birth and not the unit type (OU, AMU, and FMU) is recorded at birth registration so a mapping exercise was undertaken to map ONS hospital/unit codes for hospitals in England to the equivalent codes used in the Birthplace cohort study. This mapping was used to classify actual place of birth by type of setting.

The analysis was based on the unit type in April 2010 or on the last known unit type if the unit did not participate in the Birthplace cohort study.

Locations of birth are not coded in such a way that births in AMUs can be disaggregated from births in the associated obstetric unit. Tabulations of birth registrations were therefore obtained for the following settings: OU without AMU, OU with AMU, FMU, at home, elsewhere. We were not able to take account of units opening or closing during 2008 and 2009, so that, for example, an OU that became an FMU would be counted as an FMU throughout the period, and an OU that opened an AMU during the two year period would be counted as an OU with an AMU throughout the period.

Table 2 shows the total number of live births and the number of 'eligible' births registered in England in 2008 and 2009, tabulated by actual place of birth. 'Other or unclassified' includes NHS establishments in England which are a hybrid between an FMU and an OU and a wide range of other NHS establishments including NHS hospitals outside England where we lacked information about the type of hospital/unit. The majority of births in this category are to women who are usually resident in England, but gave birth in hospitals in Wales. 'Home births' include only births at the mother's usual place of residence.

Table 2: total number of live births and 'eligible' live births registered in England in 2008 and 2009, by actual place of birth

Place of confinement	All live births		'Eligible'* live births	
	2008 (n)	2009 (n)	2008 (n)	2009 (n)
Total	672,373	670,627	605,075	601,970
NHS establishments:	649,254	649,073	582,948	581,334
FMUs	12,761	11,045	12,383	10,839
OUs	393,274	390,490	354,569	351,926
OUs with AMUs	242,373	246,802	215,240	217,931
Other or unclassified	846	736	756	638
Non-NHS communal establishments	3,190	2,756	2,933	2,561
At Home [#]	18,884	17,778	18,251	17,151
Elsewhere ^{&}	1,045	1,020	943	924

* gestational age ≥ 37 week, singleton, birthweight ≥ 1500 g

[#] All births at mother's usual place of residence (includes unplanned home births)

[&] All places not covered above. May include some 'home' births which were not at the mother's usual place of residence.

Estimation of elective caesarean section rate for Obstetric Units

Because planned place of birth at labour onset is not a valid concept for women who deliver by elective caesarean section, we needed to estimate the proportion of 'eligible' OU births that fell into this category.

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We requested two tabulations of Hospital Episode Statistics (HES) data for the financial years 2008/09 and 2009/10. The tabulations requested were:

- Total number of delivery episodes subdivided by unit, and grouped by gestational age (<37 weeks, ≥37 weeks, unknown) and number of babies delivered (singleton, multiples, unknown)
- Total number of 'eligible' delivery episodes (singleton, gestation ≥37 weeks) by mode of delivery

The purpose of these tabulations was to estimate the approximate proportion of obstetric unit births that would not have been eligible for inclusion in the Birthplace cohort study, i.e. obstetric unit births that were preterm (gestation <37 weeks) or multiple pregnancies, or were term births (gestation ≥37 weeks) but delivered by elective caesarean section.

It was found that unit (hospital) level data were not available for many trusts with more than one maternity unit making it impossible to tabulate data on mode of delivery only for obstetric units. Additionally gestational age and/or multiplicity were missing in a substantial proportion of records (29% in 2008/09, 17% in 2009/10).

Planned home births as a proportion of all home births

When birth registration data are compiled, births which occur at the mother's usual place of residence are coded as home births. Data from this source do not distinguish between planned and unplanned home births as the registration system is not designed to collect data about health care. In this feasibility study, we did not attempt systematically to identify sources of data that might have enabled us to estimate the number of planned and unplanned home births. The Hospital Episode Statistics system does not manage to capture most home births. Some relevant data were collected in 2007 in a survey by the Healthcare Commission, now known as the Care Quality Commission.¹ Sources similar to those used by Mori² could additionally be used, although these have limitations.

Numerator data (perinatal deaths)

Intrapartum stillbirths and early neonatal deaths

The CEMACH perinatal death notification form was modified in 2006 to enable data on intended place of birth at labour onset to be recorded for all perinatal deaths. We initially planned to use perinatal mortality data for the years 2006 and 2007 for the intrapartum mortality analysis, but subsequently decided to base the analysis on data for the years 2008 and 2009 for two reasons. First, changes to the perinatal notification form introduced in 2008 meant that additional data on pre-existing medical conditions and other risk factors became available from 2008 onwards. Second, preliminary analysis indicated that the

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completeness and internal consistency of recording of intended place of birth was initially poor but improved over time. A further dataset covering all perinatal death notification for these two years was obtained from the National Patient Safety Agency in June 2011^b. All analyses described below are based on data for the years 2008 and 2009.

Identification of 'eligible' perinatal deaths

In order to identify term, singleton, intrapartum stillbirths and early neonatal deaths in England ('eligible' perinatal deaths), we applied the following exclusion criteria sequentially:

- Deaths occurring in Wales, Northern Ireland and Scotland
- Deaths recorded as fetal loss, late fetal loss, antepartum stillbirth, late neonatal death
- Preterm births (gestation < 37 weeks)
- Multiple births

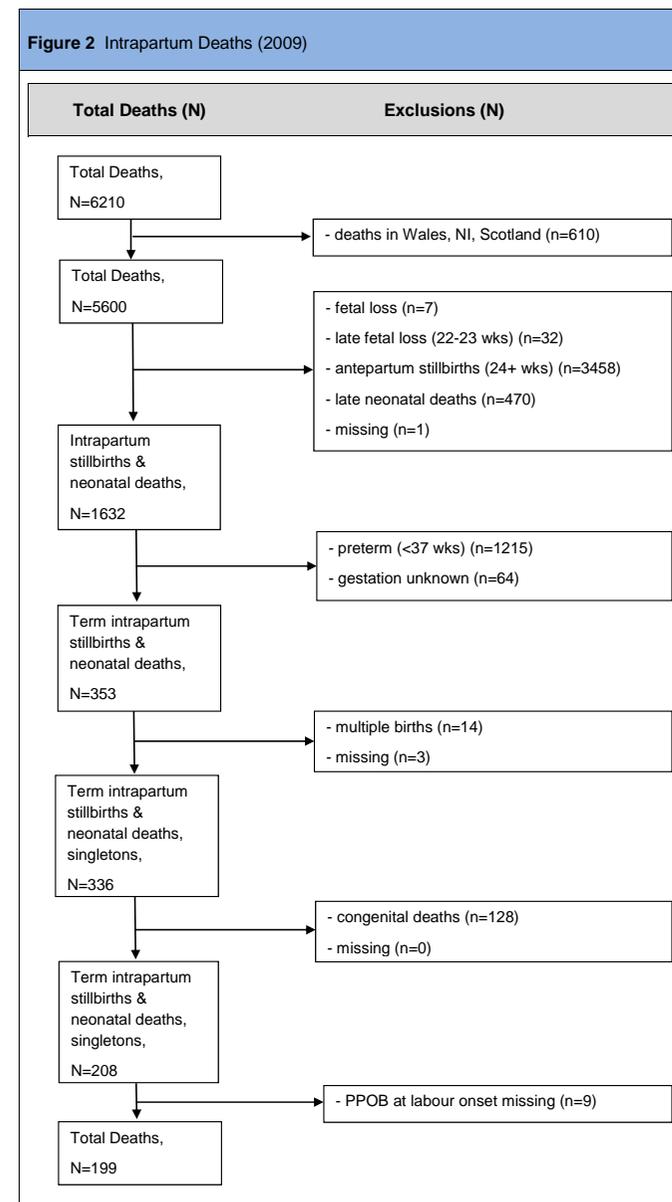
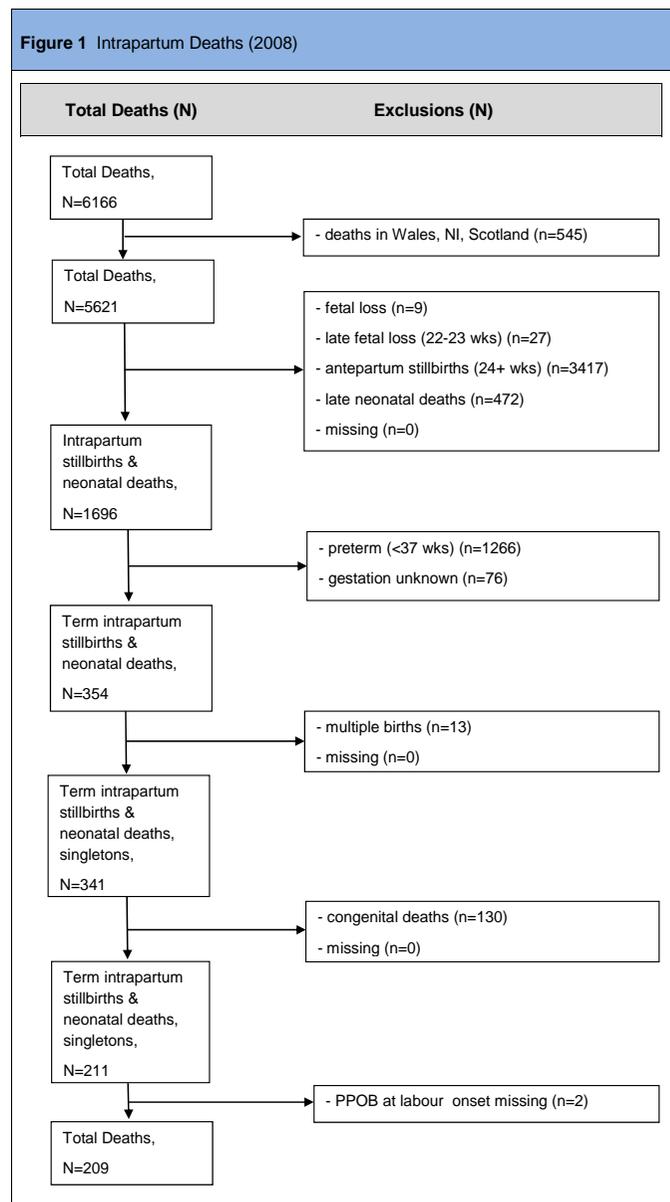
We additionally excluded:

- Deaths attributed to congenital anomalies

The flow charts in Figures 1 and 2 show the results of applying these exclusion criteria to the data. The highest level of missing data was found for gestational age which was missing for a total of 140 (4%) of 3328 records relating to intrapartum stillbirths and early neonatal deaths.

In total, we identified 211 'eligible' deaths in 2008 and 208 in 2009; intended place of birth at the onset of labour was missing for 11 (2.6%) of these.

^b The National Patient Safety Agency (NPSA) temporarily assumed responsibility for the CEMACH/CMACE legacy perinatal death data in 2011 following the closure of CMACE in March 2011.



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Analysis of deaths by intended place of birth at labour onset

The question on the perinatal death notification form relating to intended place of birth at labour onset changed between 2008 and 2009:

- In 2008, the name of the unit was recorded on the form and a tick box provided to indicate the type of unit (Obstetric unit, Midwifery Unit, Home, other). The name of the unit therefore had to be used to determine whether the unit was an FMU or an AMU attached to an OU. A mapping of unit code to unit type was provided by CMACE.
- In 2009, the name of the unit was recorded, but the tick boxes used to record the type of unit were amended so that the type of midwifery unit (AMU or FMU) could be recorded.

We tabulated the unit type variables for eligible deaths in 2008 and 2009 and reviewed the tables to identify inconsistencies (incompatible combinations such as midwifery unit birth in a hospital coded as having only an obstetric unit). We investigated these to see if they could be resolved using information about units collected during the Birthplace study, e.g. units opening or changing from an OU to MU. Using these additional data and by reviewing the full record, we were able to 'correct' all but two of the 14 inconsistently coded deaths (one home or AMU; one AMU or OU).

We did not review records for accuracy of coding where there were no obvious inconsistencies or records where an intended place of delivery at labour onset was recorded in combination with 'never in labour'.

Table 3 shows the distribution of intrapartum stillbirths and early neonatal deaths by intended place of birth at labour onset of labour (based data subject to the preliminary data cleaning described above).

Table 3: Intrapartum stillbirths and early neonatal deaths by intended place of birth at labour onset

Intended place of birth	2008	2009	Total
Obstetric Unit	150	148	298
AMU	15	6	21
FMU	7	6	13
Home	4	11	15
TOTAL eligible with known PPOB	176	172	348
Never in labour/other*	33	25	
Not Known	-	2	
Total	209	199	

* Private hospital

Internal consistency

It was immediately apparent that the numbers of intrapartum stillbirths and neonatal deaths recorded in the CEMACH/CMACE notification data were considerably lower than would have been expected based on the Birthplace cohort study data, allowing for the fact that the Birthplace cohort study collected data for a considerably shorter period than two years and, in the case of midwifery units, less than 100% of units in England participated. Of particular note:

- 16 intrapartum stillbirths and perinatal deaths were recorded in the Birthplace planned home birth group (all risks) over the equivalent of 1.37 years of national data collection compared with 15 deaths over a 2 year period in the CEMACH/CMACE perinatal notification data.
- 9 intrapartum stillbirths and perinatal deaths were recorded in the Birthplace planned FMU birth group over a study period equivalent to 0.97 years of national data collection compared with 13 perinatal deaths over a largely overlapping two year period in the CEMACH/CMACE perinatal notification dataset.

Given the rigorous data collection methods employed in the Birthplace cohort study, these findings may suggest possible under ascertainment of deaths for

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intended out of hospital births in the CEMACH/CMACE data. Intended place of birth at labour onset is not recorded in NHS data systems so may be difficult to ascertain retrospectively and it seems plausible that there may have been some misclassification of actual place of birth as intended place of birth. Another possible explanation is that discrepancies may be attributable to differences between data sources in the definitions of intended place of birth. We specified “intended place of delivery at labour onset” in the CEMACH/CMACE data, but “planned place of birth at start of care in labour” in the Birthplace cohort study. This change in definition arose from discussions within the Birthplace co-investigators group in which it was agreed that the planned place of birth could not be confirmed and recorded until labour care had actually started and that the earlier definition was potentially unreliable.

Because CMACE had ceased to exist at the time the analysis was conducted, we were unable to investigate these discrepancies further.

Identification of risk factors known prior to the onset of labour

We reviewed variables in the CMACE perinatal deaths dataset to identify conditions corresponding to the maternal risk factors listed in the NICE intrapartum care guideline.³

- The following pre-existing risk factors could be unambiguously identified:
 - Maternal BMI >35 (but relatively high levels of missing data were noted)
 - Planned caesarean sections and emergency sections carried out prior to the onset of labour
 - Twins and higher order births
 - Pre-existing diabetes
 - Pre-existing epilepsy
- Additional known risk factors not included in the NICE list, such as being ‘unbooked’ (no antenatal booking appointment) could also be identified.
- The following conditions were recorded but it was not possible to determine if these risk factors were known at the time of labour onset:
 - Breech presentation
 - Fetal growth restriction
- A number of pre-existing medical problems were recorded on the notification form but only under broader/less specific categories. For example, “endocrine disorder e.g. hypo or hyperthyroidism” compared with the more specific “hyperthyroidism” in the NICE risk factor list. These less specific pre-existing conditions included:

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- Cardiac disease
- Hypertensive disease
- Endocrine disorders
- Haematological disorders
- Renal disease
- Psychiatric disorders
- Some potentially relevant conditions were recorded only in the section “associated factors and cause of death”, and it is uncertain whether all pre-existing risk factors would have been recorded if they were not considered relevant to the death. The form changed between 2008 and 2009 and some conditions were coded only in 2009. The recorded conditions included:
 - Iso-immunisation
 - Maternal bacterial infection
- Some potentially relevant maternal and fetal conditions were recorded but these would not necessarily have been diagnosed prior to the onset of labour and were sometimes grouped in such a way that antepartum diagnoses could not be separated from conditions more likely to be diagnosed during labour or after the birth:
 - Antepartum or intrapartum haemorrhage (subclassified as praevia, abruption or uncertain)
 - Mechanical problems (e.g. uterine rupture, malpresentation)
 - Ascending infections
 - Specific fetal conditions (twin-twin transfusion, feto-maternal haemorrhage, non-immune hydrops)

A major limitation was that three frequently occurring risk factors (induction of labour, previous caesarean section and known group B strep carriage) could not be identified or reliably inferred from the data for 2008. The form was modified in 2009 to capture data on induction of labour and previous caesarean section. The approximate prevalence of these risk factors in planned OU births vs. other settings in the Birthplace cohort is shown below:

- Induction of labour: 17.6% of planned OU births vs. 0.06% in births planned in other setting
- Previous caesarean section: 4.6% of planned OU births vs. 0.5% of ‘other’ births
- Known group B strep: 3% of planned OU births vs. 0.6% of ‘other’ births

Summary of key findings

Denominator data (births by setting)

- **Actual vs. planned/intended place of birth** Most current routine data relate to actual place of birth not intended place of birth at labour onset and do not identify women who transfer from their intended place of birth during labour.
- **Number of planned home births** Birth registration is a legal process. Registration data relate to the actual place of birth and do not distinguish between planned and unplanned home births. Hospital Episode Statistics do not capture most home births and the data about those it does include are inadequate for the purposes of this study. In this feasibility study, we focused on routine data sources and did not attempt to estimate the numbers of planned and unplanned home births using data from other sources.
- **Number of AMU and OU births** Where a hospital contains both an OU and an AMU, routine data collection systems (HES and birth registration) do not currently distinguish between births that occur in the AMU and those that occur in the OU. Using routine data alone it is therefore not possible to estimate the annual number of actual births in AMUs or to estimate the number of births in OUs separately from birth occurring in adjoining AMUs
- **HES data by unit type** Some trusts do not provide unit level HES data. Where a trust contains more than one type of maternity unit, it is therefore not possible to analyse HES data by unit type (OU, AMU, FMU).

Numerator data (perinatal deaths by intended birth setting)

- The number of perinatal deaths in planned home and planned FMU births (all risks) was lower than anticipated suggesting under-ascertainment or 'misclassification'.
- The perinatal death notification form used until 2009 does not readily enable risk factors present prior to the onset of labour to be identified.

Conclusions

Our analysis suggested that there was a high risk that this modelling study would produce imprecise and potentially biased estimates of intrapartum perinatal mortality:

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- For planned births in FMUs, there appeared to be a high risk of substantial underestimation of the perinatal mortality rate.
- For obstetric unit births, the feasibility of stratifying the analysis of perinatal mortality into low and higher risk births was substantially limited by the lack of key variables needed to classify the mother's risk status prior to the onset of labour. This compromised the feasibility of producing a reliable perinatal mortality rate for the comparator group of 'low risk' planned obstetric unit births.

In view of these major limitations, the co-investigators made the recommendation to the funders that this component study should not proceed.

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