Maternal, Newborn and Infant Clinical Outcome Review Programme



### MBRRACE-UK Perinatal Mortality Surveillance Report

**Technical document** 

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on behalf of the MBRRACE-UK collaboration





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# 1. MBRRACE-UK methods for reporting perinatal mortality rates

#### 1.1 Deaths reported to MBRRACE-UK

Deaths reported to MBRRACE-UK since 1 January 2013 are:

- *late fetal losses*: a baby delivered between 22<sup>+0</sup> and 23<sup>+6</sup> weeks gestational age showing no signs of life, irrespective of when the death occurred;
- *stillbirths*: a baby delivered at or after 24<sup>+0</sup> weeks gestational age showing no signs of life, irrespective of when the death occurred;
- *neonatal deaths*: a liveborn baby (born at 20<sup>+0</sup> weeks gestational age or later) who died before 28 completed days after birth.

These definitions also include any late fetal loss, stillbirth, or neonatal death resulting from a termination of pregnancy.

In an effort to ensure complete data collection and to facilitate international comparisons, the eligibility criteria for MBRRACE-UK are based on gestational age at delivery irrespective of when the death occurred. Therefore, all births delivered from 22<sup>+0</sup> weeks gestational age showing no signs of life must be reported, irrespective of when the death occurred; the date of delivery and date of confirmation of death are both reported for these deaths. For all deaths, where an accurate estimate of gestation is not available a minimum birthweight of 400g is used to determine eligibility.

MBRRACE-UK has established a secure online reporting system which can be accessed by all UK Trusts and Health Boards. Responsibility for reporting a death and for the completeness and the quality of the data reported to MBRRACE-UK lies with the Trust or Health Board where the death occurred. Each Trust and Health Board has identified a small number of MBRRACE-UK Lead Reporters who act as key points of contact between their organisation and MBRRACE-UK. In order to check for any relevant deaths that have not been reported to MBRRACE-UK, details of statutorily registered deaths are obtained from the Office for National Statistics (ONS) (England and Wales), National Records of Scotland (NRS) (Scotland), Northern Ireland Maternity System (NIMATS) and Northern Ireland Statistics and Research Agency (NISRA) (Northern Ireland), Health Intelligence Unit (Bailiwick of Jersey) and Health and Social Services Department (Bailiwick of Guernsey). More details of the MBRRACE-UK reporting system are given in Section 3.

#### 1.2 Information collected by MBRRACE-UK

Comprehensive information about each death is requested by MBRRACE-UK in order to allow detailed examination of the risk factors for perinatal mortality in the UK. Data items are collected with the aims of, first, offering more appropriate adjustment of the crude mortality rates than had previously been possible and, second, providing a clearer insight into the health, social and lifestyle factors most commonly associated with stillbirth or neonatal death. The data relating to each death consists of information about the following:

- mother's and baby's identifying information (to permit the cross-checking of each death against other national databases and to facilitate the identification of duplicate records);
- mother's health, lifestyle and previous pregnancy history;
- mother's antenatal care;
- labour and delivery;
- cause of death and post-mortem examination.

Details of the data requested for each late fetal loss, stillbirth and neonatal death can be found in Section 4. Approvals have been obtained from all relevant authorities in order for identifiable data to be collected without consent and to access statutory birth and death information (Section 3).

#### **1.3 The birth cohort**

Rates of stillbirth, neonatal death and extended perinatal death are presented for births from 1 January to 31 December in the reported year; thus, neonatal deaths of babies born in December 2018 which occurred in January 2019 are included in the report for 2018 births. The reporting of mortality for a birth cohort is in contrast to statutory publications, which are based on *deaths* in a calendar year. This method of reporting allows more accurate estimates of mortality rates to be produced as appropriate denominators are available.

Individual level information on all births in the UK and Crown Dependencies is obtained in order to generate mortality rates adjusted for maternal, baby, and socio-demographic risk factors. Information for England, Wales and the Isle of Man (Personal Demographics Service (PDS) and ONS birth registration data), Scotland (NRS and Public Health Scotland; PHS), Northern Ireland (NIMATS), Bailiwick of Guernsey (Health and Social Services Department) and the Bailiwick of Jersey (Health Intelligence Unit) are combined to give a single dataset of births for the whole UK and Crown Dependencies. This data is then combined with the information on the deaths to obtain the final data for analysis. Details of the generation of the births dataset are provided in Section 3.

It is important to note that, since 29 April 2016, NHS Digital removes certain patient records from data provided for England where a patient has requested an opt-out. The NHS Constitution states "You have the right to request that your confidential information is not used beyond your own care and treatment and to have your objections considered". To support those NHS constitutional rights, patients within England are able to opt out from their personal confidential information being shared by NHS Digital for purposes other than their own direct care; this is known as the 'Type 2 opt-out'. Patients are able to register the opt-out at their GP practice.

#### 1.4 Deaths included in reported mortality rates

In order to facilitate the comparability of mortality rates between organisations, and unless stated otherwise, **births less than 24<sup>+0</sup> weeks gestational age and terminations of pregnancy are excluded from the mortality rates reported in the main maps and tables**. This avoids the influence of the wide disparity in the classification of babies born before 24<sup>+0</sup> weeks gestational age as a neonatal death or a fetal loss, as well as the known variation in the rate of termination of pregnancy for congenital anomaly across the UK. The mortality rates reported include all eligible deaths, including deaths due to congenital anomalies, unless stated otherwise.

The number of deaths of babies born in the UK in the reported year as described by MBRRACE-UK will differ from that of statutorily registered deaths published by ONS (England and Wales), NRS (Scotland) and NISRA (Northern Ireland) because of the exclusion criteria used in this report to ensure standardisation of mortality rates. It is important to recognise that data sources from statutorily registered births and deaths include both birth and death registrations following termination of pregnancy from 24<sup>+0</sup> weeks gestational age and variable inclusion of births at 23<sup>+6</sup> weeks gestational age and below, depending on whether they were reported as being liveborn or not. MBRRACE-UK receives stillbirth and neonatal death registrations from statutory sources. This data is matched to the detailed MBRRACE-UK death notifications. Of these registered deaths, neonatal deaths are excluded if delivery was before 24<sup>+0</sup> weeks gestational age or they were a termination of pregnancy (deaths are classified as resulting from a termination of pregnancy based on the detailed MBRRACE-UK data).

In addition to registered deaths obtained from ONS, PHS and NISRA, additional deaths are reported to MBRRACE-UK for:

- the small number of deaths statutorily registered with ONS, PHS or NISRA only after considerable delay, most often because an inquest was being held;
- late fetal losses delivered at 22<sup>+0</sup> to 23<sup>+6</sup> weeks gestational age which are not subject to statutory registration;

stillbirths delivered at 24<sup>+0</sup> weeks gestational age or greater where the death was confirmed before 24<sup>+0</sup> weeks gestational age; these are not routinely registered as stillbirths, as recommended by RCOG guidance and agreed with the Department of Health [1, 2].

#### **1.5** Organisations for which mortality rates are reported

Rates of stillbirth, neonatal death, and extended perinatal death are reported for four groups of clinical and administrative organisations:

- 1. Organisations responsible for population-based care commissioning based on postcode of mother's residence at time of delivery:
  - England: Clinical Commissioning Groups (CCGs); Sustainability and Transformation Partnerships (STP);
  - Scotland: National and Health Boards;
  - Wales: National and Health Boards;
  - Northern Ireland: National and Local Commissioning Groups;
  - Crown Dependencies: Isle of Man, Bailiwick of Guernsey, and Bailiwick of Jersey.
- 2. Service delivery organisations based on place of birth:
  - England: NHS Trusts;
  - Scotland: Health Boards;
  - Wales: Health Boards;
  - Northern Ireland: Health and Social Care Trusts;
  - Crown Dependencies: Isle of Man, Bailiwick of Guernsey, and Bailiwick of Jersey.
- 3. UK Neonatal Networks based on place of birth.
- 4. Local government areas based on postcode of mother's residence at time of delivery:
  - England: Single tier authorities, upper tier authorities and London boroughs;
  - Scotland: Unitary authorities;
  - Wales: Local authorities;
  - Northern Ireland: Local government districts;
  - Crown Dependencies: Isle of Man, Bailiwick of Guernsey, and Bailiwick of Jersey.

#### **1.6 Analysis of mortality rates**

Three mortality outcomes are reported for each organisation: stillbirth, neonatal death, and extended perinatal death. These mortality rates are presented in a number of different ways: as a 'crude' mortality rate, a 'stabilised' mortality rate and a 'stabilised & adjusted' mortality rate.

The **crude mortality rate** is the number of deaths divided by the number of total births (or live births in the case of neonatal mortality) for the reported year and provides an annual snapshot of the mortality in an organisation.

While the crude rate is informative, in that it describes exactly what happened for the organisation, it can be potentially misleading when trying to highlight organisations where the mortality rate is higher than expected due to variation in the quality of care. The number of perinatal deaths for many organisations is likely to be small, as these deaths are rare, and there will be more deaths in some years than in others just by chance. This

can lead to large fluctuations in the annual crude mortality rate, especially for organisations that have a very small number of births.

In order to compare organisations more fairly, **stabilised mortality rates** are calculated and presented alongside the crude mortality rates. Where there is only a small number of births in an organisation it is difficult in any one year to be sure that any extreme value seen for the crude mortality rate is real and not just a chance finding. A *stabilised* rate allows for the effects of chance variation due to small numbers. For this reason, the stabilised mortality rate will tend to be closer to the average mortality rate than will the crude mortality rate, especially for organisations with a small number of births. For organisations commissioning care or carrying out public health initiatives to reduce perinatal mortality, crude and stabilised mortality rates are presented followed by a table detailing the risk factor profiles for each population to facilitate the development and targeting of interventions.

For service delivery organisations, some organisations have a higher proportion than others of women at high risk of experiencing a stillbirth or neonatal death: for example, they provide a national or regional specialist service or serve areas of high socio-economic deprivation. Thus the case-mix of the service users can influence mortality rates even when high quality maternity and neonatal care is provided. The mortality rates for service delivery organisations are, therefore, also *adjusted* to account for key factors which are known to increase the risk of perinatal mortality: i.e. **stabilised & adjusted mortality rates**. The extent of the adjustment is limited to those factors that are collected for all births across the whole of the UK: mother's age; socio-economic deprivation based on the mother's residence; baby's ethnicity; baby's sex; whether they are from a multiple birth; and gestational age at birth (neonatal deaths only). Therefore, some factors that might be associated with poor perinatal outcomes could not be taken into account in the adjustment because they are not universally collected on all births; for example, maternal smoking and body mass index (BMI). As for stabilised rates, the stabilised & adjusted mortality rate will also tend to be closer to the average mortality rate than will the crude mortality rate, especially for organisations with a small number of births.

It is important to remember that the mortality rates reported are not definitive measures of the quality of care received by any individual or group. Some of the variation in mortality rates shown in the report might be the result of differences in the proportion of high-risk pregnancies that cannot be accounted for in the analyses due to a lack of routinely collected detailed clinical information for all births (as described above). However, given the information that is available, the rates reported by MBRRACE-UK are robust and make an important contribution in highlighting those organisations where extra investigations should be targeted in order to improve the quality of perinatal and neonatal care in the UK.

#### 1.7 Identifying potentially high and low rates of death

The crude, stabilised and stabilised & adjusted mortality rates are presented as both tables and maps. In the maps, each organisation is colour coded based on the extent to which their particular mortality rate is above or below the 'average' mortality rate. For the organisations based on the postcodes of the mothers' residences at time of delivery, and for Neonatal Networks, this average is the overall observed mortality rate for the whole of the UK and the Crown Dependencies.

However, it is known that service delivery organisations based on the place of birth vary widely in the risk profile of pregnancies referred to their service; therefore, it is reasonable to anticipate variation in their expected mortality rates. To help account for the variation due to the risk profile, all Trusts and Health Boards are classified hierarchically into five mutually exclusive comparator groups based on their level of service provision and are compared to the average mortality rate within their comparator group. The five comparator groups are:

- 1. Level 3 Neonatal Intensive Care Unit (NICU) and neonatal surgery;
- 2. Level 3 NICU;
- 3. 4,000 or more births per annum at 22 weeks or later;
- 4. 2,000-3,999 births per annum at 22 weeks or later;

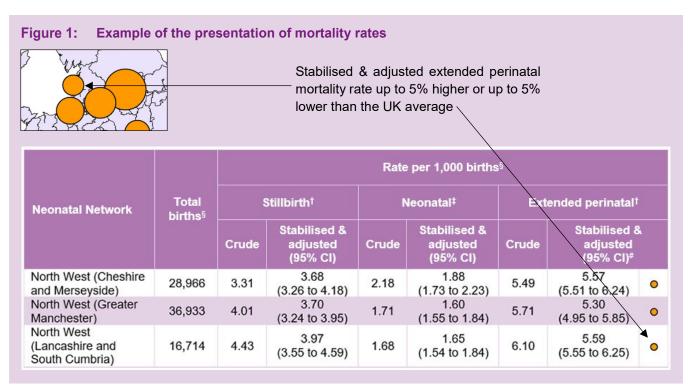
5. Under 2,000 births per annum at 22 weeks or later.

For reported years 2017 onwards the colour coding used in the maps and tables is as follows:

- Green: more than 15% lower than the average.
- Yellow: more than 5% and up to 15% lower than the average.
- Amber: up to 5% higher or up to 5% lower than the average.
- Red: more than 5% higher than the average.

The size of the circles on each map represents the number of births in the population covered by the particular organisation, although there is a minimum size in order that the colour can be adequately seen.

The accompanying tables show either both the crude and the stabilised rate for stillbirth, neonatal death, and extended perinatal death or the crude and the stabilised & adjusted rate for stillbirth, neonatal death, and extended perinatal death for each organisation, as appropriate, and are presented in the format shown in Figure 1. In order to avoid the effect of any local policy decisions regarding the classification of live and stillbirth at the extremes of viability, particular emphasis is given to the extended perinatal mortality rate and each organisation has been colour coded based on their crude, stabilised or stabilised & adjusted extended perinatal mortality rate in an identical manner to the maps.



#### 1.8 Suppression of rates calculated when there are few deaths

In order to avoid disclosure of information which could potentially identify individuals, crude mortality rates based on a very small number of deaths are not included, in line with guidance from ONS [3] and the Government Statistical Service [4]. Suppressed mortality rates are shown as a white dot (O) on the maps and as an asterisk in the tables, where appropriate.

# 2. Statistical methods to calculate stabilised & adjusted mortality rates

The stabilised & adjusted mortality rate for each organisation  $(m_j)$  is calculated by multiplying the appropriate 'comparator' mortality rate (M) by an organisation-specific standardised mortality ratio  $(SMR_j)$  calculated from the data, i.e.:

 $m_i = M \times SMR_i$ 

where  $m_j$  is the estimated stabilised & adjusted mortality rate for organisation j

*M* is the appropriate comparator mortality rate

*SMR*<sub>*j*</sub> is the estimated SMR for organisation *j*:  $SMR_j = \frac{(\text{No. observed deaths})}{(\text{No. expected deaths})}$ 

Currently, for all organisations, except for the Trusts and Health Boards of birth, the comparator mortality rate is the overall mortality rate for the whole of the UK and Crown Dependencies. For the Trusts and Health Boards of birth the comparator mortality rate is the overall rate for Trusts and Health Boards in the same comparator group (described below). The SMR is estimated using a multilevel logistic regression model:

$$\operatorname{logit}\left[P_{ij}\left(Y_{ij}=1\big|\mathbf{x}_{ij}\right)\right]=\alpha+\beta\mathbf{x}_{ij}+\mathbf{\Gamma}\mathbf{z}_{j}+\delta_{j}$$

where  $Y_{ij}$  is the indicator variable of death for the *i*<sup>th</sup> baby in the *j*<sup>th</sup> organisation:

 $Y_{ij} = 1$  if a death, 0 otherwise

 $x_{ij}$  is the vector of risk-adjustment factors for the *i*<sup>th</sup> baby in the *j*<sup>th</sup> organisation

 $z_i$  is the vector of risk-adjustment factors for the *j*<sup>th</sup> organisation

 $\delta_i$  is the random term representing organisation *j*:  $\delta \sim \text{Normal}(0,\sigma^2)$ 

A multilevel model is used as it can accommodate the hierarchical structure of the data through the random term; that is, births clustered within organisations. These models also allow the calculation of stabilised (also known as 'shrunken' or 'smoothed') estimates of the organisation-specific terms, which reduce the likelihood of organisations being falsely identified as outliers by chance alone.

Various approaches to calculating a SMR from a multilevel logistic model have been proposed [5]. The method used for the MBRRACE-UK report "... *is determined by dividing the smoothed, risk-adjusted, provider-specific estimate of mortality by the estimate of expected mortality obtained using the average intercept for all ... providers*" [6]. In this approach, the observed number of deaths is replaced by a model-based predicted number reflecting sampling variation in the observed deaths; that is, a stabilised observed number of deaths is estimated for each organisation. Hence, the SMR is the ratio of the stabilised number of deaths to the deaths that would be expected if the organisation's patients were from an 'average' organisation:

$$SMR_{j} = \frac{\sum_{i=1}^{n_{j}} \frac{\exp\left[\alpha + \beta \mathbf{x}_{ij} + \Gamma \mathbf{z}_{j} + \delta_{j}\right]}{\left[1 + \exp\left[\alpha + \beta \mathbf{x}_{ij} + \Gamma \mathbf{z}_{j}\right]\right]}}{\sum_{i=1}^{n_{j}} \frac{\exp\left[\alpha + \beta \mathbf{x}_{ij} + \Gamma \mathbf{z}_{j}\right]}{\left[1 + \exp\left[\alpha + \beta \mathbf{x}_{ij} + \Gamma \mathbf{z}_{j}\right]\right]}} \text{ and } m_{j} = M \times \frac{\frac{\sum_{i=1}^{n_{j}} \frac{\exp\left[\alpha + \beta \mathbf{x}_{ij} + \Gamma \mathbf{z}_{j} + \delta_{j}\right]}{\left[1 + \exp\left[\alpha + \beta \mathbf{x}_{ij} + \Gamma \mathbf{z}_{j}\right]\right]}}{\sum_{i=1}^{n_{j}} \frac{\exp\left[\alpha + \beta \mathbf{x}_{ij} + \Gamma \mathbf{z}_{j}\right]}{\left[1 + \exp\left[\alpha + \beta \mathbf{x}_{ij} + \Gamma \mathbf{z}_{j}\right]\right]}}$$

#### **Risk-adjustment factors**

For service delivery organisations the multilevel logistic regression model outlined in the previous section includes patient-level and organisation–level factors to adjust for differences in key factors which are known to increase the risk of stillbirth and neonatal mortality. The factors which can be included in the model are limited to those that are routinely collected for all births across the whole UK. For this report the patient-level risk-adjustment factors included in the statistical model were:

- mother's age (<20 years, 20-24 years, 25-29 years, 30-34 years, 35-39 years, ≥40 years);
- child poverty (measured by Children in Low Income Families Local Measure [7] based on mother's residence (quintiles with approximately equal number of total births);
- baby's ethnicity (White, mixed or multiple ethnicity, Asian or Asian British, Black or Black British, other);
- baby's sex (male, non-male);
- multiple birth (singleton, multiple);
- interaction between child poverty and baby's ethnicity;
- interaction between child poverty and mother's age;
- gestational age at birth for neonatal death rates only (24<sup>+0</sup> to 27<sup>+6</sup> weeks, 28<sup>+0</sup> to 31<sup>+6</sup> weeks, 32<sup>+0</sup> to 33<sup>+6</sup> weeks, 34<sup>+0</sup> to 36<sup>+6</sup> weeks, 37<sup>+0</sup> to 41<sup>+6</sup> weeks, ≥42<sup>+0</sup> weeks).

The only organisation-level factor ( $z_{ij}$ ) currently included in the MBRRACE-UK analysis is a marker for the 'comparator group' of each organisation responsible for delivering maternity care. In the absence of detailed clinical data, to help account for the variation between organisations due to their differences in risk profile, all of the Trusts and Health Boards have been classified hierarchically into five mutually exclusive comparator groups based on their level of service provision. They are then compared to the average mortality rate within their comparator group. The five comparator groups are:

- 1. Availability of Level 3 NICU and Neonatal Surgery;
- 2. Availability of Level 3 NICU;
- 3. 4,000 or more births per annum at 24 weeks or later;
- 4. 2,000-3,999 births per annum at 24 weeks or later;
- 5. Under 2,000 births per annum at 24 weeks or later.

#### **Statistical models**

Two multilevel logistic regression models are used, one for the stillbirths as outcome and the other model for neonatal deaths. The reference group for the both models is the births surviving at least 28 days from birth. The multilevel logistic regression model for stillbirth compared to survival to the end of the neonatal period is:

$$\operatorname{logit}\left[P_{(SB)ij}\left(Y_{(SB)ij}=1\big|\mathbf{x}_{ij}\right)\right]=\alpha_{(SB)}+\beta_{(SB)}\mathbf{x}_{ij}+\Gamma_{(SB)}\mathbf{z}_{j}+\delta_{(SB)j}$$

where  $Y_{(SB)ij}$  is the indicator variable of stillbirth for the *i*<sup>th</sup> baby in the *j*<sup>th</sup> organisation:

Y<sub>(SB)ij</sub> = 1 if stillbirth; 0 if survivor to end of neonatal period; missing if neonatal death;

 $x_{ij}$  is the vector of risk adjustment factors for the *i*<sup>th</sup> baby in the *j*<sup>th</sup> organisation;

 $z_{ij}$  is the vector of risk adjustment factors for the *j*<sup>th</sup> organisation;

 $\delta_{(SB)j}$  is the random term representing organisation *j*:  $\delta \sim \text{Normal}(0,\sigma^2)$ .

A similar model is estimated for neonatal deaths:

$$\operatorname{logit}\left[P_{(NND)ij}\left(Y_{(NND)ij}=1\big|\mathbf{x}_{ij}\right)\right]=\alpha_{(NND)}+\beta_{(NND)}\mathbf{x}_{ij}+\Gamma_{(NND)}\mathbf{z}_{j}+\delta_{(NND)j}$$

where  $Y_{(NND)ij}$  is the indicator variable of neonatal death for the *i*<sup>th</sup> baby in the *j*<sup>th</sup> organisation:

Y(NND)ij = 1 if neonatal death; 0 if survivor to end of neonatal period; missing if stillbirth;

 $x_{ij}$  is the vector of risk adjustment factors for the *i*<sup>th</sup> baby in the *j*<sup>th</sup> organisation;

 $z_{ij}$  is the vector of risk adjustment factors for the *j*<sup>th</sup> organisation;

 $\delta_{(NND)j}$  is the random term representing organisation *j*:  $\delta \sim \text{Normal}(0,\sigma^2)$ .

The SMR for stillbirth is then given by combining these two models:

$$SMR_{(SB)j} = \frac{\sum_{i=1}^{n_j} \left[ \frac{\exp(\alpha_{(SB)} + \beta_{(SB)} \mathbf{x}_{ij} + \Gamma_{(SB)} \mathbf{z}_j + \delta_{(SB)j})}{1 + \exp(\alpha_{(SB)} + \beta_{(SB)} \mathbf{x}_{ij} + \Gamma_{(SB)} \mathbf{z}_j + \delta_{(SB)j}) + \exp(\alpha_{(NND)} + \beta_{(NND)} \mathbf{x}_{ij} + \Gamma_{(NND)} \mathbf{z}_j + \delta_{(NND)j})}{\sum_{i=1}^{n_j} \left[ \frac{\exp(\alpha_{(SB)} + \beta_{(SB)} \mathbf{x}_{ij} + \Gamma_{(SB)} \mathbf{z}_j)}{1 + \exp(\alpha_{(SB)} + \beta_{(SB)} \mathbf{x}_{ij} + \Gamma_{(SB)} \mathbf{z}_j) + \exp(\alpha_{NND} + \beta_{(NND)} \mathbf{x}_{ij} + \Gamma_{(NND)} \mathbf{z}_j)} \right]}$$

The SMR for neonatal deaths is derived directly from the second multilevel logistic regression model since stillbirths are not included in the calculation of neonatal death rates:

$$\mathsf{SMR}_{(\mathsf{NND})j} = \frac{\sum_{i=1}^{n_j} \left[ \frac{\exp(\alpha_{(\mathsf{NND})} + \beta_{(\mathsf{NND})} \mathbf{x}_{ij} + \Gamma_{(\mathsf{NND})} \mathbf{z}_j + \delta_{(\mathsf{NND})j})}{1 + \exp(\alpha_{(\mathsf{NND})} + \beta_{(\mathsf{NND})} \mathbf{x}_{ij} + \Gamma_{(\mathsf{NND})} \mathbf{z}_j + \delta_{(\mathsf{NND})j})} \right]}{\sum_{i=1}^{n_j} \left[ \frac{\exp(\alpha_{(\mathsf{NND})} + \beta_{(\mathsf{NND})} \mathbf{x}_{ij} + \Gamma_{(\mathsf{NND})} \mathbf{z}_j)}{1 + \exp(\alpha_{(\mathsf{NND})} + \beta_{(\mathsf{NND})} \mathbf{x}_{ij} + \Gamma_{(\mathsf{NND})} \mathbf{z}_j)} \right]}$$

The SMR for the extended perinatal deaths is obtained by combining the results of both models:

$$\mathsf{SMR}_{(\mathsf{EPD})j} = \frac{\sum_{i=1}^{n_j} \left[ \frac{\exp(\alpha_{(SB)} + \beta_{(SB)} \mathbf{x}_{ij} + \Gamma_{(SB)} \mathbf{z}_j + \delta_{(SB)j}) + \exp(\alpha_{(NND)} + \beta_{(NND)} \mathbf{x}_{ij} + \Gamma_{(NND)} \mathbf{z}_j + \delta_{(NND)j})}{1 + \exp(\alpha_{(SB)} + \beta_{(SB)} \mathbf{x}_{ij} + \Gamma_{(SB)} \mathbf{z}_j + \delta_{(SB)j}) + \exp(\alpha_{(NND)} + \beta_{(NND)} \mathbf{x}_{ij} + \Gamma_{(NND)} \mathbf{z}_j + \delta_{(NND)j})} \right]} \\ \frac{\sum_{i=1}^{n_j} \left[ \frac{\exp(\alpha_{(SB)} + \beta_{(SB)} \mathbf{x}_{ij} + \Gamma_{(SB)} \mathbf{z}_j) + \exp(\alpha_{(NND)} + \beta_{(NND)} \mathbf{x}_{ij} + \Gamma_{(NND)} \mathbf{z}_j)}{1 + \exp(\alpha_{(SB)} + \beta_{(SB)} \mathbf{x}_{ij} + \Gamma_{(SB)} \mathbf{z}_j) + \exp(\alpha_{(NND)} + \beta_{(NND)} \mathbf{x}_{ij} + \Gamma_{(NND)} \mathbf{z}_j)} \right]}{\mathbf{x}_{i=1}^{n_j} \left[ \frac{\exp(\alpha_{(SB)} + \beta_{(SB)} \mathbf{x}_{ij} + \Gamma_{(SB)} \mathbf{z}_j) + \exp(\alpha_{(NND)} + \beta_{(NND)} \mathbf{x}_{ij} + \Gamma_{(NND)} \mathbf{z}_j)}{1 + \exp(\alpha_{(SB)} + \beta_{(SB)} \mathbf{x}_{ij} + \Gamma_{(SB)} \mathbf{z}_j) + \exp(\alpha_{(NND)} + \beta_{(NND)} \mathbf{x}_{ij} + \Gamma_{(NND)} \mathbf{z}_j)} \right]} \right]}$$

#### 95% confidence intervals

The reported 95% confidence intervals for the stabilised & adjusted mortality rate are obtained through bootstrap methods [8]:

- 1. J organisations are sampled with replacement (where J is the total number of organisations).
- 2. The multilevel model is estimated for the sample, keeping each appearance of an organisation distinct if it is sampled more than once.
- 3. The estimated value, and prediction error, of the random term is obtained for each organisation:  $\delta_j$  and error( $\delta_j$ ) if an organisation is sampled more than once then a single set of values is selected at random.
- 4. The bootstrap estimates for the fixed terms are noted ( $\alpha^*$ ,  $\beta^*$  and  $\Gamma^*$ ).
- 5. A new value ( $\delta_j^*$ ) for the organisation-specific random term is sampled, where  $\delta_j^* \sim N(\delta_j^*$ , erfor[ $\delta_j$ ]).

- 6. The bootstrap stabilised & adjusted mortality rate  $(m_j^*)$  is obtained by substituting  $(\alpha^*, \beta^*, \Gamma^* \text{ and } \delta_j^*$  for  $\alpha, \beta, \Gamma$  and  $\delta_j$  as appropriate.
- 7. This is repeated 1,500 times, giving approximately 1,000 values for the bootstrap stabilised & adjusted mortality rate for each organisation since organisations are not necessarily included in each bootstrap sample.
- The lower and upper limits of the 95% confidence interval are obtained for each organisation from the 2.5<sup>th</sup> and 97.5<sup>th</sup> percentiles respectively of the distribution the bootstrap stabilised & adjusted mortality rates.

#### Probability of falling above a benchmark

The statistical methodology used allows the calculation of empirical Bayes posterior probabilities to estimate the probability that the underlying mortality rate for an organisation falls above (or below) a specified benchmark; for example, it would be possible to report the probability that the underlying stabilised & adjusted mortality rate for organisation *j* is greater than 6 per 1,000 births ( $m_j > 6.0$ ). In this report, organisations have been identified when the probability that they fall above, or below, a specified benchmark is greater than 0.5; that is, 'it is more likely than not' that their underlying mortality rate falls outside the benchmark.

#### Missing data

Where information is unavailable for the risk-adjustment factors because it is missing from the routine data source, in order to allow all appropriate births to be included in the analyses the missing values are assumed to fall into the following categories:

- mother's age 30 to 34 years;
- socio-economic deprivation middle quintile;
- baby's ethnicity white;
- baby's sex male;
- multiple birth singleton;
- gestational age at birth 37<sup>+0</sup> to 41<sup>+6</sup> weeks.

Since missing observations are imputed with values generally representing low risk groups, stabilised & adjusted mortality rates are potentially overestimated for those organisations with missing data. However, as the proportion of missing data is low, and the effect of adjustment is relatively small, any overestimation will be small and unlikely to change any conclusions inferred from the reported rates.

# 3. Further details of MBRRACE-UK data collection

#### 3.1 Approvals for collection of patient identifiable data

The necessary approvals obtained by the MNI-CORP programme prior to the start of the data collection process are listed below. These are applied for in order to collect patient identifiable data and access information collected by statutory organisations without consent.

### Box 1: Approvals granted for UK collection of patient identifiable data and access to statutory data without consent

#### England and Wales

The Confidentiality Advisory Group of the Health Research Authority:

ECC 5-05 (f)/2012 (from 10.10.2012); 15/CAG/0119 (from 01.05.2015)

Health & Social Care Information Centre, Data Access Advisory Group: IC604DS

#### Scotland

The NHS Scotland Caldicott Guardian: 2014-62 MBRRACE-UK Programme – Update (2013-05)

The Privacy Advisory Committee, ISD, NHS National Services Scotland: PAC16/14

#### **Northern Ireland**

Due to the different data privacy arrangements in Northern Ireland only de-identified data is provided to the MNI-CORP programme and this is supplied by the NIMACH office

#### 3.2 The system for online data submission

#### Security

Access to the MBRRACE-UK website is via the internet using the secure HTTPS protocol. The web and database servers are housed in a secure data centre with firewall protection. All staff requesting online access must be approved by their Trust or Health Board and log-in is only possible with either an NHS or UK university email address. When an approved reporter first accesses the website they are required to request an activation code. This is used as a one-time password which must be changed on first access. All passwords must meet a set of criteria which ensures all passwords accepted are 'strong'. Reporters are assigned to a profile which restricts their access to only the appropriate parts of the website for their role (the system is used to report deaths, to review deaths with the PMRT, and to provide access to anonymised medical case notes for assessors taking part in MBRRACE-UK confidential enquiries).

All patient identifiers are encrypted before they are stored. Access to identifiable data is only allowed under very limited circumstances. Reporters may view the data from their own Trust or Health Board (subject to the use of a valid password) while access to identifiable data by MBRRACE-UK staff is subject to NHS information governance, security and confidentiality regulation (Box 1).

#### Data integrity and validation

Reporters wishing to report a new death or edit an existing death record are required to confirm the mother's details (NHS or CHI number, name, date of birth) on each occasion. The nationally defined algorithm for checking NHS and CHI numbers is used to ensure only valid numbers are entered.

Where appropriate, the information reported is checked against a range of acceptable values during the data entry process. For each such data item there is a range of expected values and an absolute range. If a value is outside the expected range the reporter is warned and informed of the range. If it is outside the absolute range then the value cannot be entered and, additionally, the record cannot be closed. Before the reporter can close a record additional checks are carried out; for example, date values across the whole record are validated against each other to test for consistency.

In some circumstances there may be a small number of data items that are unavailable. In these situations reporters may indicate that an item is 'not known', with an opportunity to add the missing data at a later date,

For a significant number of deaths some of the data required will be held in more than one hospital, e.g. some aspects of maternal data after the death of a baby following postnatal transfer. If the additional information is held within the same Trust or Health Board but on a different site then reporters can access all the information they need in collaboration with obstetric, midwifery, neonatal or nursing colleagues. However, if the missing information is held by a different Trust or Health Board then the MBRRACE-UK system allows the reporter to temporarily assign ownership of the MBRRACE-UK record to the other Trust or Health Board who can then return it once the missing information has been provided.

#### **Online help**

Help is available on every data entry screen through Frequently Asked Questions (FAQs). In addition, many of the variables have specific help available by clicking on the 'Help' icon. Also, on every screen of the website there is a function to allow the reporter to enter a help request. This is sent via email to the MBRRACE-UK office for attention by the technical, clinical or administrative staff, as appropriate. A detailed user manual is also available to download from the MBRRACE-UK system.

#### Reports

The MBRRACE-UK online reporting system allows access to information relating to local deaths:

- the Trust/Health Board Case Summary list provides abbreviated details of all deaths reported in an individual birth year together with the current status of each case's surveillance form and Perinatal Mortality Review Tool review;
- the Trust/Health Board Reported Cases list provides abbreviated details of all deaths reported;
- the Trust/Health Board Summary provides the number of deaths by year, case-type and unit;
- the Trust/Health Board Case Review list provides the opportunity for local reporters to check the accuracy (within a fixed time frame) of the data reported by their organisation prior to the analysis for the report.

In addition, users can access a real-time data monitoring tool which allows them to view, filter and summarise live surveillance data for their Trust.

#### Web browser compatibility

The security requirements of the NHS in relation to electronic data flows mandate that the highest levels of security be employed. In order for this to be achieved, those accessing the MBRRACE-UK reporting system need access to an up-to-date web browser compatible with these security specifications. Appropriate browsers are available to download free of charge, although the installation of such software may require the co-operation of local NHS IT departments.

# 3.3 Ensuring all births and extended perinatal deaths are identified

The sources of data used to ensure complete data collection of births and extended perinatal deaths for this cohort are listed in Box 2. The combining and checking of this data is outlined below.

#### Box 2: Data sources for the ascertainment of UK births and perinatal deaths

#### England and Wales

Birth registration data – ONS

Death registration data - ONS

PDS data on all births – NHS Digital (PDS)

#### Scotland

Birth registration data – NRS

Death registration data - NRS

Maternity Inpatient and Day Case Dataset (SMR02) inpatient data - PHS, NHS National Statistics Scotland

#### **Northern Ireland**

Birth registration data - NIMACH, Health and Social Care Public Health Agency - derived from NIMATS

Death registration data - NIMACH, Health and Social Care Public Health Agency - derived from NIMATS

Inpatient data - NIMACH, Health and Social Care Public Health Agency - derived from NIMATS

#### **Crown Dependencies**

Birth registration data - Health and Social Services Department, States of Guernsey

Death registration data - Health and Social Services Department, States of Guernsey

Birth registration data - Health Intelligence Unit, Public Health Services, States of Jersey

Death registration data - Health Intelligence Unit, Public Health Services, States of Jersey

PDS data on all births, Isle of Man – NHS Digital (PDS)

#### Identifying all extended perinatal deaths

Statutorily registered deaths which meet the MBRRACE-UK reporting criteria are matched to the deaths reported to MBRRACE-UK in order to identify any stillbirths or neonatal deaths which have not been reported to MBRRACE-UK. Due to the different system of implementation in Northern Ireland, the NIMACH office staff ensured full ascertainment of their data on our behalf.

For England, Wales and Scotland the matching is performed using a combination of deterministic and probabilistic matching methods based on the mother's given name, mother's family name, postcode of residence at time of delivery, Trust or Health Board of birth, baby's NHS number (England – where available), CHI number (Scotland), gestational age at delivery, birthweight, date of delivery and date of death.

Once the checking is complete the MBRRACE-UK Lead Reporters are notified of any known deaths that have occurred in their Trust or Health Board which could not be identified on the MBRRACE-UK system and asked to confirm that this was a death in their organisation and provide the missing information.

This checking for deaths missing from the MBRRACE-UK database cannot start until information on statutorily registered deaths are provided to MBRRACE-UK by ONS (England and Wales) and NRS (Scotland), meaning that we cannot inform MBRRACE-UK Lead Reporters of missing deaths until some months after the event. Although most missing deaths can be identified in this way, not all deaths to be reported to MBRRACE-UK are available from statutory sources in a timely manner:

- 1. A small percentage of statutorily registered deaths are registered only after considerable delay, most often because an inquest was being held;
- 2. Late fetal losses delivered at 22<sup>+0</sup> to 23<sup>+6</sup> weeks gestational age are not officially registered;
- 3. RCOG guidance [1, 2] is that stillbirths delivered at 24<sup>+0</sup> weeks gestational age or greater where the death was confirmed before 24<sup>+0</sup> weeks gestational age should not be registered as stillbirths; however, in order to investigate variations in the reporting of stillbirths occurring at around 24<sup>+0</sup> weeks gestational age, these deaths should all be reported to MBRRACE-UK.

There are no timely and easily accessible data sources for deaths that have not been officially registered and, therefore, it is not possible to ensure that all of these deaths have been reported to MBRRACE-UK.

#### Identifying all births

Individual information on all births in the UK and Crown Dependencies is obtained in order to generate mortality rates adjusted for maternal, baby, and socio-demographic risk factors. Information for England, Wales and the Isle of Man (PDS and ONS birth registration data), Scotland (NRS and PHS), Northern Ireland (NIMATS), Bailiwick of Guernsey (Health and Social Services Department) and the Bailiwick of Jersey (Health Intelligence Unit) is combined to give a single dataset of births for the whole UK and Crown Dependencies. This data is then combined with the information on the deaths to obtain the final data for analysis.

The allocation of births to an organisation is complex, given the wide variation in the recording of the notifying organisation, and it is not always possible to easily identify the place of birth from the data reported. In many cases this either requires further detailed enquiry or correction of the place of birth, where an incorrect organisation has inadvertently been recorded. Complete and accurate recording is vital to enable MBRRACE-UK to allocate births to the appropriate Trust or Health Board for analysis and reporting.

Home births are allocated to the Trust or Health Board responsible for this service, whenever this is recorded, in order for the correct denominator(s) to be calculated. All Trusts and Health Boards in England, Wales and the Isle of Man completing information for the PDS should ensure that they are identified as the notifying organisation for all births related to their service.

#### 3.4 Generating the births dataset

The births and extended perinatal deaths identified using the sources and methods described above are combined to generate a single dataset for analysis. Due to the variations in the data sources from the different countries, this is undertaken separately for each set of data sources as described below. Once the datasets have been generated for each country these are combined into a final, single dataset for analysis.

#### **England and Wales**

The complete dataset of births and extended perinatal deaths for England and Wales is generated using birth registration data (ONS), death registration data (ONS), PDS records, and MBRRACE-UK death notification records:

Step 1: All datasets are restricted to births in the reported year.

Step 2: All records of births are combined into a single dataset (Figure 2): i.e. livebirth registrations (ONS); stillbirth registrations (ONS); PDS birth records; MBRRACE-UK notifications of late fetal losses. All of these datasets are used in order to obtain complete ascertainment of all births in England and Wales:

- late fetal losses are only recorded in the MBRRACE-UK death records;
- late birth registrations are captured by the PDS records;
- birth records removed from the PDS data because of patient opt-outs are captured by the ONS births records.

Step 3: Births at less than 22<sup>+0</sup> weeks gestational age and pregnancies ended by a termination of pregnancy are removed from the dataset of births as these are not reported by MBRRACE-UK.

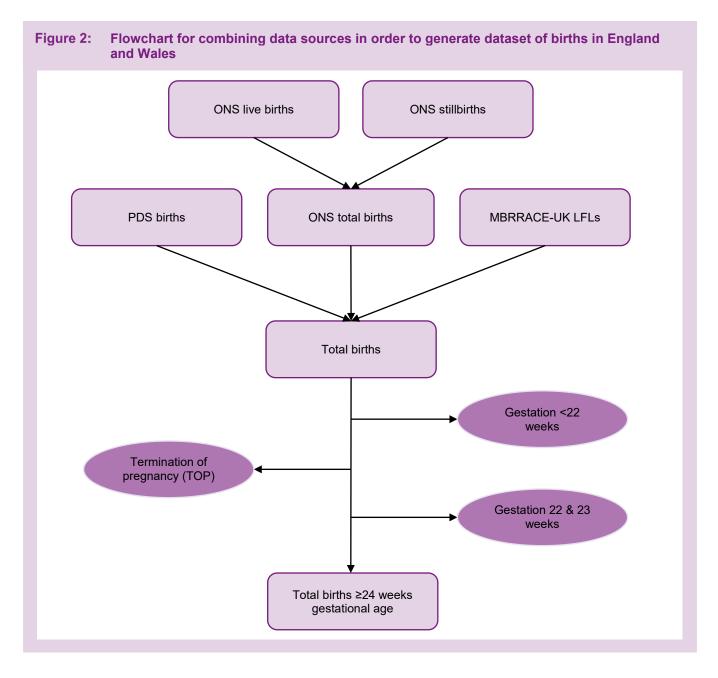
Step 4: Births at 22<sup>+0</sup> to 23<sup>+6</sup> weeks gestational age are removed from the dataset of births for the main tables and maps as these births are currently reported separately by MBRRACE-UK.

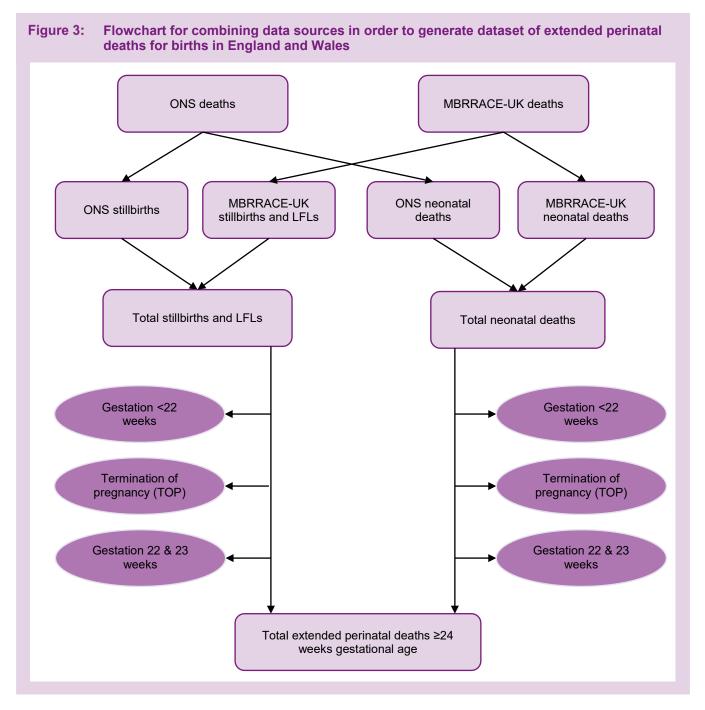
Step 5: All records of late fetal losses, stillbirths, and neonatal deaths are combined into a single dataset (Figure 3): i.e. death registrations (ONS); MBRRACE-UK death notifications. Both of these datasets are used in order to obtain complete ascertainment of all extended perinatal deaths in England and Wales.

Step 6: All deaths where the births occurred at less than 22<sup>+0</sup> weeks gestational age and pregnancies ended by a termination of pregnancy are removed from the dataset of deaths as these are not reported by MBRRACE-UK.

Step 7: All deaths where the births occurred at less than 24<sup>+0</sup> weeks gestational age are removed from the dataset of deaths for the main tables and maps as these deaths are currently reported separately by MBRRACE-UK.

Step 8: The dataset of deaths are merged into the dataset of births in order to create a single dataset for analysis.





#### Scotland

The complete dataset of births and extended perinatal deaths for Scotland is generated using a similar approach to that used for England and Wales. For Scotland, data is obtained from birth registration data (NRS), death registration data (NRS), SMR02 Maternity Inpatient and Day Care Case records (PHS), and MBRRACE-UK death notification records. The birth registration data and the SMR02 data are merged before being released to MBRRACE-UK (PHS). The process undertaken by MBRRACE-UK is:

Step 1: All datasets are restricted to births in the reported year.

Step 2: All records of births are combined into a single dataset (Figure 4): i.e. birth registrations/SMR02 (PHS); PHS notifications of late fetal losses; MBRRACE-UK notifications of late fetal losses. These datasets are used in order to obtain complete ascertainment of all births in Scotland:

Step 3: Births at less than 22<sup>+0</sup> weeks gestational age and pregnancies ended by a termination of pregnancy are removed from the dataset of births as these are not reported by MBRRACE-UK.

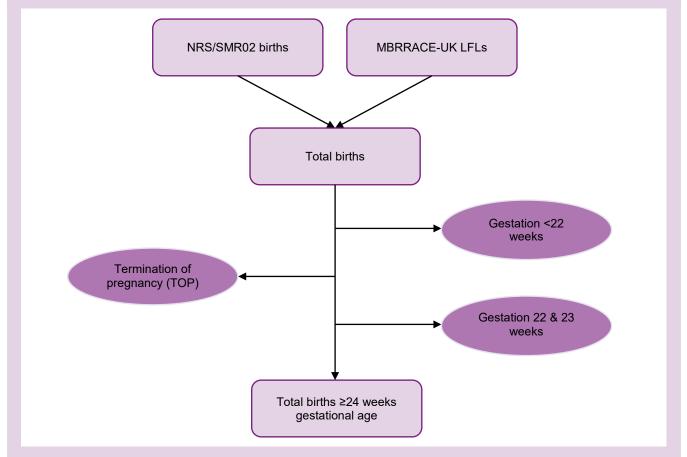
Step 4: Births at 22<sup>+0</sup> to 23<sup>+6</sup> weeks gestational age are removed from the dataset of births for the main tables and maps as these births are currently reported separately by MBRRACE-UK.

Step 5: All records of late fetal losses, stillbirths, and neonatal deaths are combined into a single dataset (Figure 5): i.e. death registrations and SMR02 (PHS); MBRRACE-UK death notifications. Both of these datasets are used in order to obtain complete ascertainment of all extended perinatal deaths in Scotland.

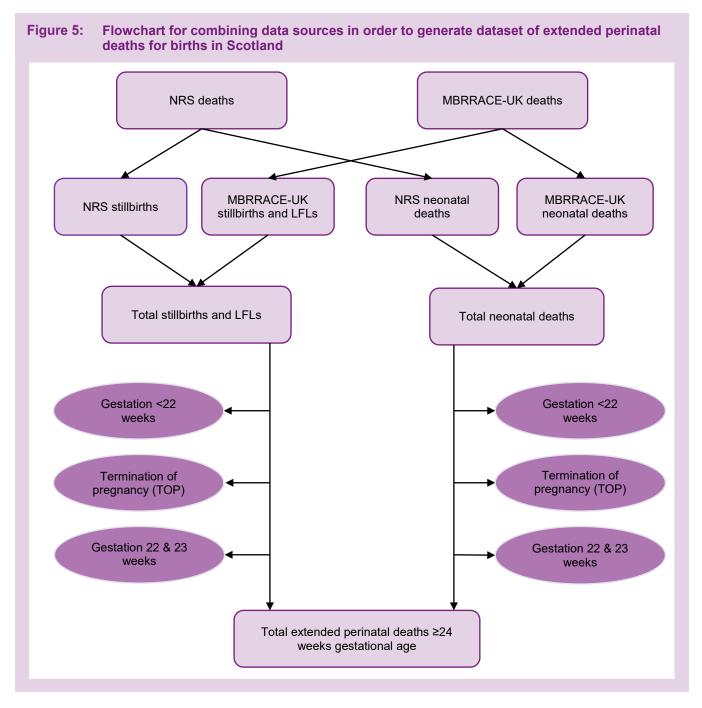
Step 6: All deaths where the births occurred at less than 22<sup>+0</sup> weeks gestational age and pregnancies ended by a termination of pregnancy are removed from the dataset of deaths as these are not reported by MBRRACE-UK.

Step 7: All deaths where the births occurred at less than 24<sup>+0</sup> weeks gestational age are removed from the dataset of deaths for the main tables and maps as these deaths are currently reported separately by MBRRACE-UK.

Step 8: The dataset of deaths is merged into the dataset of births in order to create a single dataset for analysis.



#### Figure 4: Flowchart for combining data sources in order to generate dataset of births in Scotland



#### Northern Ireland and the Crown Dependencies

Datasets of births and extended perinatal deaths for Northern Ireland, the Bailiwick of Guernsey, and the Bailiwick for Jersey are supplied to MBRRACE-UK as complete datasets from the appropriate national data providers. The birth records for the Isle of Man are obtained from the PDS records. In each case the birth and death records are then linked to the MBRRACE-UK records.

#### Data cleaning, linking and derived variables

Where information on a variable is available from more than one source a 'best value' algorithm is applied in order to obtain the value to be included in the analyses. The algorithm chosen is:

- where available, the value recorded in the MBRRACE-UK death record is used as the prime source;
- if unavailable (e.g. the baby survived the neonatal period) the value recorded in the statutory birth or death registration record is taken as the secondary source;

• for England and Wales, the value recorded in the PDS record is used as the third source: the gestational age at delivery is only available from the PDS records.

#### 3.5 Location of mother's residence

The postcode of the mother's residence at the time of delivery is used to identify the country, CCG (England), Health Board (Scotland and Wales), Health and Social Care Trust (Northern Ireland), Crown Dependency, and Local Authority of reporting using postcode linked data supplied as part of GridLink. In addition, it is used to obtain the appropriate value for the child poverty index.

The Trust or Health Board of birth is derived using the most appropriate source from all available datasets. For England and Wales the recorded Communal Establishment Code in the ONS birth records is used as the primary source the location of the birth. When the place of birth cannot not be located from the ONS records (e.g. births at home and in-transit) the location is derived from the PDS record. If neither record provided a clear Trust or Health Board of birth then an estimate is made based on the postcode of birth.

The Trust or Health Board of death is obtained directly from the MBRRACE-UK death record.

# 4. Description of the data items reported to MBRRACE-UK

#### Woman's identifiers

Family name/surname Given name/first name Address Postcode NHS/Community Health Index (CHI) number Date of birth/Age Hospital number in this hospital

#### Woman's details Ethnic category

Country of birth Time resident in the UK at booking Documented communication difficulties? Type of communication difficulties Age at leaving full-time education Main support during pregnancy Employment status at booking Did woman have a partner? Partner's employment status at booking Blood relationship of woman to baby's father Was woman refugee or asylum seeker? Woman's health Pre-existing medical problems

Tobacco smoking status Electronic cigarette use Breath carbon monoxide Weekly alcohol consumption pre-pregnancy d Weekly alcohol consumption at booking <sup>d</sup> Was there documented alcohol abuse? Was there documented substance abuse? Confirmed positive test for COVID-19 infection? e Previous pregnancies<sup>a</sup> Outcome for fetus Birthweight Infant death Year Gestational age Fetal anomaly Obstetric history Number of previous pregnancies Previous pregnancy complications Booking Intended type of unit at booking Intended type of care at booking Intended care provider at booking Date of first booking appointment Final estimated date of delivery (EDD) Basis for EDD Number of fetuses present at booking/ultrasound Chorionicity

Assisted conception

Woman's height in cm

Woman's first recorded weight in kg Was woman too heavy for hospital scales? First recorded BMI (if height/weight unavailable) Documented influenza vaccination in this pregnancy?

Date of vaccination

#### Antenatal care provision

Number of antenatal appointments attended Documented poor appointment attender Intended type of unit at onset Intended type of care at onset Intended care provider at onset Reason if transfer of care (between booking and onset) Actual type of unit at delivery Actual type of care at delivery Actual care provider at delivery Reason if transfer of care (post-onset) Delivery and outcomes summary <sup>a</sup> Case definition Was this a termination? Reason for termination Labour and delivery Onset of labour Date of onset of care in labour Time of onset of care in labour Time of onset of labour Prolonged rupture of membranes (>24 hours) Date of rupture Presentation at delivery Attempted modes of delivery Final mode of delivery Type of caesarean section Primary indication for caesarean section Was the baby born in water? **Delivery complications** Date of deliverv/birth Time of delivery/birth Were blood gases done? Source of the blood gases Arterial: Cord pH Base excess/deficit Lactate Venous: Cord pH Base excess/deficit Lactate Baby/fetus outcomes <sup>a</sup> NHS/CHI number Sex of baby/fetus Ethnic category Birth order Birthweight Gestational age at delivery Confirmed positive test for COVID-19 infection? e Was a heartbeat present in the first minute? Heartbeat rate band Was a cord pulse present in the first minute? Cord pulse rate band Active body movement in first minute Respiratory activity in first minute Apgar score at 1 minute

#### Baby/fetus outcomes (cont'd) a

Was active respiratory support provided? Reason if no active respiratory support provided Outcome if active respiratory support provided Minutes after which active respiratory support attempts were stopped Were there documented child protection issues? Was there documented history of domestic abuse? Gestational age at confirmation of death <sup>b</sup> Date death confirmed <sup>b</sup> Was baby alive at onset of care process that led to deliverv? b Was baby admitted to a neonatal unit? ° Was baby transferred to another organisation after birth? ° Primary reason for the first transfer ° Number of transfers <sup>c</sup> Type of unit where death occurred <sup>c</sup> Care provider at time of death ° Was the death unattended? ° Date of death ° Time of death ° Cause of death a Sources of information used to determine cause of death Was a mortality review undertaken for this case? Types of mortality review that apply Cause of death as written in notes or on the death certificate Primary cause of death: condition CODAC code Baby/fetus associated condition: condition CODAC code Is this the final, agreed cause of death following any inquest and all requested investigations? Post-mortem Was a post-mortem offered? Was consent given for a post-mortem? Consented post-mortem procedures Was a post-mortem undertaken? Undertaken procedures Was the placenta sent for histology? Was the case discussed with a coroner/procurator fiscal Was the case accepted as a corner/procurator fiscal's case? Clinicians Obstetrician responsible for care Neonatologist/paediatrician responsible for care <sup>a</sup> recorded for each baby/fetus <sup>b</sup> stillbirth and late fetal losses only

- <sup>c</sup> live births only
- <sup>d</sup> collected until December 2016
- <sup>e</sup> collected from March 2020

Apgar score at 5 minutes

### **Definitions used in the report**

Late fetal loss	A baby delivered between 22 <sup>+0</sup> and 23 <sup>+6</sup> weeks gestational age showing no signs of life, irrespective of when the death occurred.
Stillbirth	A baby delivered at or after 24 <sup>+0</sup> weeks gestational age showing no signs of life, irrespective of when the death occurred.
Antepartum stillbirth	A baby delivered at or after 24 <sup>+0</sup> weeks gestational age showing no signs of life and known to have died before the onset of care in labour.
Intrapartum stillbirth	A baby delivered at or after 24 <sup>+0</sup> weeks gestational age showing no signs of life and known to have been alive at the onset of care in labour.
Neonatal death	A liveborn baby (born at 20 <sup>+0</sup> weeks gestational age or later, or with a birthweight of 400g or more where an accurate estimate of gestation is not available), who died before 28 completed days after birth.
Early neonatal death	A liveborn baby (born at 20 <sup>+0</sup> weeks gestational age or later, or with a birthweight of 400g or more where an accurate estimate of gestation is not available) who died before 7 completed days after birth.
Late neonatal death	A liveborn baby (born at 20 <sup>+0</sup> weeks gestational age or later, or with a birthweight of 400g or more where an accurate estimate of gestation is not available) who died after 7 completed days but before 28 completed days after birth.
Perinatal death	A stillbirth or early neonatal death.
Extended perinatal death	A stillbirth or neonatal death.
Termination of pregnancy	The deliberate ending of a pregnancy, normally carried out before the embryo or fetus is capable of independent life.

# **Abbreviations**

BMI	Body Mass Index
CCG	Clinical Commissioning Group
СНІ	Community Health Index (Scotland)
CI	Confidence Interval
CODAC	Cause Of Death & Associated Conditions
EDD	Estimated Date of Delivery
FAQ	Frequently Asked Questions
HQIP	Healthcare Quality Improvement Partnership
LFL	Late Fetal Loss
MBRRACE-UK	Mothers and Babies: Reducing Risk through Audits and Confidential Enquiries across the UK
MNI-CORP	Maternal, Newborn and Infant Clinical Outcome Review Programme
NICU	Neonatal Intensive Care Unit
NIMACH	Northern Ireland Maternal and Child Health
NIMATS	Northern Ireland Maternity System
NISRA	Northern Ireland Statistics and Research Agency
NRS	National Records of Scotland
ONS	Office for National Statistics
PDS	Personal Demographics Service
PHS	Public Health Scotland
PMRT	Perinatal Mortality Review Tool
RCOG	Royal College of Obstetricians and Gynaecologists
SMR	Standardised Mortality Ratio
SMR02	Maternity Inpatient and Day Case Dataset (Scotland)
STP	Sustainability and Transformation Partnership

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Version	Details of changes	Release date
1.0	First release	10/12/2020
1.1	Data sources for Scotland updated	14/10/2021
1.2	References updated	13/10/2021