Maternal, Newborn and Infant Clinical Outcome Review Programme

MBRRACE-UK
Mothers and Babies: Reducing Risk through Audits and Confidential Enquiries across the UK

# MBRRACE-UK
# Perinatal Mortality Surveillance Report

## UK Perinatal Deaths for Births from January to December 2014

## EXECUTIVE SUMMARY

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University of Oxford · HQIP Healthcare Quality Improvement Partnership · University of Leicester · TIMMS · University of Birmingham · Sands Stillbirth & neonatal death charity · UCL · NHS Bradford Teaching Hospitals NHS Foundation Trust · npeu National Perinatal Epidemiology Unit

# Executive Summary

## Background

This is the second UK perinatal surveillance report produced under the auspices of the Maternal, Newborn and Infant Clinical Outcome Review Programme (MNI-CORP). The programme is commissioned by the Healthcare Quality Improvement Partnership (HQIP) on behalf of NHS England, NHS Wales, the Scottish Government Health and Social Care Directorate, the Northern Ireland Department of Health, Social Services and Public Safety (DHSSPS), the States of Guernsey, the States of Jersey, and the Isle of Man Government. The report has been produced by MBRRACE-UK, a collaboration led from the National Perinatal Epidemiology Unit at the University of Oxford with members from the University of Leicester, who lead the perinatal aspects of the work, University of Liverpool, University of Birmingham, University College London, Bradford Teaching Hospitals NHS Foundation Trust, a general practitioner from Oxford, and Sands, the stillbirth and neonatal death charity.

The scope of the MNI-CORP programme has four main elements. This report focuses on:

> **Surveillance of all late fetal losses ($22^{+0}$ to $23^{+6}$ weeks gestational age), stillbirths, and neonatal deaths.**

## Methods

Deaths to be reported to MBRRACE-UK since 1 January 2013 through the secure online reporting system are:

- late fetal losses: a baby delivered between $22^{+0}$ and $23^{+6}$ weeks gestational age showing no signs of life, irrespective of when the death occurred;
- stillbirths: a baby delivered at or after $24^{+0}$ weeks gestational age showing no signs of life, irrespective of when the death occurred;
- neonatal deaths: a liveborn baby (born at $20^{+0}$ 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.

Individual level information on all births in the UK 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 (NHS Numbers for Babies (NN4B) and Office for National Statistics (ONS) birth registration data), Scotland (National Records Scotland (NRS) and Information Services Division (ISD)), Northern Ireland (Northern Ireland Maternity System (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 of the UK and the Crown Dependencies. This data is then combined with the information on the deaths to obtain the final data for analysis.

# Analysis

The main findings of the report are represented in a combination of maps and tables showing both the crude and the stabilised & adjusted mortality rates for stillbirths, neonatal deaths, and extended perinatal deaths (stillbirth and neonatal deaths combined). In order to ensure comparability of mortality rates between organisations, births less than $24^{+0}$ weeks gestational age and terminations of pregnancy have been excluded from the reported mortality rates. This avoids the influence of the wide disparity in the classification of babies born before $24^{+0}$ weeks gestational age as a neonatal death or a fetal loss and the known variation in the rate of termination of pregnancy for congenital anomaly across the UK.

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

- organisations responsible for population based care commissioning based on postcode of mother's residence at time of delivery;
- service delivery organisations based on place of birth;
- Neonatal Networks based on place of birth;
- Local Government areas based on postcode of mother's residence at time of delivery.

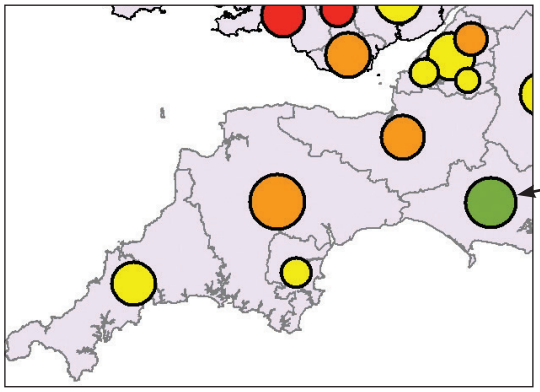
The interpretation of any mortality rate is affected by the extent to which there is variation in the disease severity of the cases for any particular organisation or geographical area when compared to elsewhere. In order to provide a more reliable comparison, the data produced in this report is shown both as 'crude' mortality rates and as 'stabilised & adjusted' mortality rates. This method of adjustment takes into account the effects of chance variation and also allows for key factors which are known to increase the risk of perinatal mortality in order to identify those organisations which, statistically, have mortality rates above or below a particular benchmark. In this report, data is presented compared to either the UK average or, for Trusts and Health Boards of birth, the average mortality in similar organisations.

# Reported mortality rates

The data in the main report is shown for the relevant commissioning and service delivery organisations, with the mortality analysis based on the mother's address at the time the birth occurred and the place of birth, respectively. There are separate maps for stillbirths, neonatal deaths, and extended perinatal deaths. For each type of mortality a pair of maps is presented: one showing the crude rate and the other showing the stabilised & adjusted rate. The size of each circle on the map broadly represents the number of births in 2014 for the particular organisation and the colour represents their rates of mortality in comparison to the appropriate average rate. Aspirational rates have also been included based on estimated equivalent rates in the Nordic countries (Norway, Sweden, Denmark, Finland, and Iceland): 3.0 stillbirths per 1,000 births; 1.3 neonatal deaths per 1,000 live births; 4.3 extended perinatal deaths per 1,000 births:

- dark green: lower than the ‘aspirational’ target;
- light green: more than 10% lower than average;
- yellow: up to 10% lower than average;
- amber: up to 10% higher than average;
- red: more than 10% higher than average.

Within the tables particular emphasis has been given to the extended perinatal death rate which has been colour coded, again based on comparison to the relevant average following the same principle as described for the maps. An example of the how the tables and maps appear is shown below:



Stabilised & adjusted extended perinatal mortality rate more than 10% lower than the UK average.

| Organisation | Total births§ | Rate per 1,000 births§ | | | | | | |
|---|---|---|---|---|---|---|---|---|
| | | Stillbirth† | | Neonatal‡ | | Extended perinatal† | | |
| | | Crude | Stabilised & adjusted (95% CI) | Crude | Stabilised & adjusted (95% CI) | Crude | Stabilised & adjusted (95% CI)# | |
| Dorset | 7,377 | 2.58 | 3.61 (2.87 to 4.80) | 0.95 | 1.50 (1.09 to 2.20) | 3.52 | 5.09 (4.06 to 6.39) | |
| Northern, Eastern and West Devon | 9,067 | 4.52 | 4.57 (3.71 to 5.96) | 1.55 | 1.71 (1.23 to 2.50) | 6.07 | 6.29 (5.30 to 7.69) | |
| South Devon and Torbay | 2,721 | * | 4.09 (3.10 to 5.51) | * | 1.57 (1.07 to 2.47) | 4.41 | 5.63 (4.47 to 7.31) | |

All organisations identified as having a stabilised & adjusted stillbirth, neonatal, or extended perinatal mortality rate that falls in the red band should conduct a local review. This should include data checking for case validation and data quality, followed by a full review of the care provision for all stillbirths and neonatal deaths, to identify any local factors which might be responsible for their reported high stabilised & adjusted mortality rate and establish whether there are potentially avoidable factors that could be managed differently.

While the UK average mortality rate, or that of similar service delivery organisations, has been used again in this MBRRACE-UK report, MBRRACE-UK will be working closely with all UK NHS and relevant professional organisations to set benchmarks for stillbirths and neonatal mortality that properly reflect national aspirations.

# Key Findings

1. In 2014 the number of births to mothers resident in the UK and Crown Dependencies at $24^{+0}$ weeks gestational age or later (excluding terminations of pregnancy) showed little change from 2013: 782,311 births compared with 781,932. There was a small decrease in the number of stillbirths (3,252 compared with 3,286) and neonatal deaths (1,381 compared with 1,436). The crude extended perinatal mortality rate was 5.92 per 1,000 total births, comprising 4.16 stillbirths per 1,000 total births and 1.77 neonatal deaths per 1,000 live births. These mortality rates are still higher than those reported by the best performing countries in Europe.
2. Significant variation in the rates of extended perinatal mortality across the UK persist, even after taking into account the effects of chance variation relating to small numbers of births in some organisations and adjusting for the case-mix differences. Amongst organisations responsible for commissioning care, stabilised & adjusted rates varied from 4.9 to 7.1 deaths per 1,000 total births.
3. Extended perinatal mortality rates have been calculated for Trusts and Health Boards using five comparator groups based on the number of births and the on-site availability of high level neonatal care in order to account for differences in the risk profile of women giving birth at these organisations. The average extended perinatal mortality rate for organisations delivering less than 2,000 births per annum was 4.2 deaths per 1,000 total births and 7.3 deaths per 1,000 total births in organisations with neonatal surgical provision and a Level 3 Neonatal Intensive Care Unit.
4. Stabilised & adjusted extended perinatal mortality rates varied within each comparator group of Trusts and Health Boards. This was particularly evident for organisations with neonatal surgical provision and a Level 3 Neonatal Intensive Care Unit: 6.0 to 9.7 deaths per 1,000 total births.
5. The percentage of extended perinatal deaths with a congenital anomaly recorded as the primary cause of death ranged from 0% to 53% for Trusts and Health Boards based on place of birth.
6. Over 90% of families who experienced a stillbirth or neonatal death were offered a post-mortem examination. In 45% of Trusts and Health Boards this offer was made for all stillbirths and neonatal deaths within their organisation, whereas 22% of organisations offered a post-mortem for less than 90% of deaths.
7. Overall, parental consent for a post-mortem was received for approximately 40% of all stillbirths and neonatal deaths.
8. The analysis of the mortality associated with the 2014 birth cohort has again identified particular areas in the UK where mortality rates are greater than 10% higher than average.
9. Pregnancies to women living in areas with the highest levels of social deprivation in the UK are over 50% more likely to end in stillbirth or neonatal death compared to births from the least deprived areas of the UK. Babies of Black or Black British and Asian or Asian British ethnicity had the highest risk of extended perinatal mortality with rates of 9.9 and 8.7 per 1,000 total births, respectively.
10. Overall, engagement of Trusts and Health Boards in the process of reporting stillbirths and neonatal deaths to MBRRACE-UK has improved. However, while some Trusts and Health Boards consistently report deaths to MBRRACE-UK in a timely fashion, for other, apparently similar, organisations the reporting of deaths appears less organised.

# Recommendations

1. All organisations identified as having a stabilised & adjusted extended perinatal mortality rate that falls in the red or amber band should conduct a local review. This should include data checking for case validation and data quality followed by a full review of the care provision for all stillbirths and neonatal deaths in order to identify any local factors which might be responsible for their reported high stabilised & adjusted mortality rate. The review should also establish whether there are lessons to be learned to improve the quality of care provision within their organisation.

2. All organisations, irrespective of their extended perinatal mortality rate, should investigate individual stillbirths and neonatal deaths using a standardised process and independent, multidisciplinary peer review as recommended in the Report of the Morecambe Bay Investigation [1]. The information within the MBRRACE-UK Perinatal Surveillance Reports (including the reports for individual Trusts and Health Boards) and recommendations from MBRRACE-UK Confidential Enquiries can facilitate this process [2, 3].

3. NHS England, NHS Scotland, NHS Wales, Health and Social Care in Northern Ireland, in conjunction with professional bodies and national healthcare advisors responsible for clinical standards in the relevant specialties (where in existence), should establish targets that reflect each country's aspirations for rates of stillbirths, neonatal deaths, and extended perinatal deaths against which services can be assessed in future.

4. All organisations responsible for maternity services should have systematic processes in place in order to ensure that all babies born between $22^{+0}$ and $23^{+6}$ weeks gestational age who are not alive at delivery or who do not survive the neonatal period are reported to MBRRACE-UK. This will ensure international consistency of extended perinatal mortality rates which are not possible from current routine registration sources.

5. It is essential that all Trusts and Health Boards provide data which is complete, accurate and reported in a timely manner in order that the most accurate comparative mortality estimates can be calculated and used for quality assurance. In particular, this should be achieved by:

    a. improving the provision of maternal data for both stillbirths and neonatal deaths;

    b. ensuring that all relevant deaths are reported to MBRRACE-UK, including those where the baby was discharged home or to a hospice for palliative care;

    c. ensuring complete and accurate notification of statutory data required for all births under their care to routine sources, including all home births.

6. All Trusts and Health Boards should work closely with MBRRACE-UK to improve their coding of the cause of death, based on the Cause Of Death & Associated Conditions (CODAC) classification system, in order to facilitate the appropriate targeting of interventions to reduce specific types of death.

7. A post-mortem examination should be offered in all cases of stillbirth and neonatal death in order to identify the cause of death where possible, to exclude potential contributory factors, and to improve the future pregnancy counselling of parents. For stillbirths, regardless of whether consent is provided for post-mortem examination, the placenta should always be submitted for histological examination, preferably by a specialist pathologist.

## References


1. Kirkup B. *The Report of the Morecambe Bay Investigation: An independent investigation into the management, delivery and outcomes of care provided by the maternity and neonatal services at the University Hospitals of Morecambe Bay NHS Foundation Trust from January 2004 to June 2013 available online at: https://www.gov.uk/government/publications*, 2015.
2. Draper ES, Kurinczuk JJ, Kenyon S, on behalf of MBRRACE-UK. *MBRRACE-UK 2015 Perinatal Confidential Enquiry: Term, singleton, normally-formed, antepartum stillbirth*. The Infant Mortality and Morbidity Studies, Department of Health Sciences, University of Leicester: Leicester, 2015.
3. Field DJ, Hyman-Taylor P, Bacon C, Draper ES, on behalf of MBRRACE-UK. *Perinatal confidential Enquiry - Congenital Diaphragmatic Hernia*. The Infant Mortality and Morbidity Studies Department of Health Sciences University of Leicester: Leicester, 2014.

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