Perinatal Mortality Surveillance Report

UK Perinatal Deaths
for births from
January to December 2013

Executive Summary

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Executive Summary

Background

This is the first 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, a general practitioner from Oxford, and Sands, the stillbirth and neonatal death charity. Previously this work has been carried out under different organisational arrangements and providers. The last of the previous reports was produced by the Centre for Maternal and Child Enquiries (CMACE) in 2011 relating to deaths in 2009.

The scope of the MNI-CORP 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.

Important changes in the approach to surveillance

MBRRACE-UK has introduced two important changes to the data collection compared to previous surveillance reports:

1. The introduction of a new system for classifying deaths. Following consultation with experts the Cause of Death and Associated Conditions (CODAC) classification system was chosen as it was felt this would provide: a) a greater understanding of the factors associated with antepartum stillbirths; b) sufficient detail about cause of death to allow the effect of serious congenital anomalies (which show considerable geographic variation) to be adequately identified and, where appropriate, excluded from the analyses.

2. The widening of inclusion criteria to include all late fetal losses as well as neonatal deaths at 22+0 to 23+6 weeks gestational age. Such losses, which have been collected at times in the past, are not part of the statutory ‘death certification’ process. However, there is evidence that these babies contribute significantly to local variation in mortality rates and data about these babies are essential for international comparisons to be meaningful.

Methods

Once the contract for the perinatal aspects of the MNI-CORP was in place in the summer of 2012 the following were undertaken in order that data collection could recommence for 2013:

a) Creation of an agreed dataset to be collected for each death;

b) Establishment of a secure on-line data entry system (the system went live in April 2013);
c) Acquisition of the necessary approvals to receive, hold and analyse the data from Trusts and Health Boards.

d) Acquisition of approvals, and the establishment of systems, to access routine data (for the purposes of cross checking and providing denominators) from each of the four countries of the UK and the Crown Dependencies. For Northern Ireland much of this process was carried out locally.

e) Establishing MBRRACE-UK Lead Reporters within all of the relevant Trusts and Health Boards in order that deaths could be reported and information on data completeness and quality fed back.

**Analysis**

The interpretation of any mortality rate is affected by the extent to which there is variation in the disease severity of the cases cared for by a particular organisation or geographical area when compared to elsewhere. In order to provide a more reliable comparison, the data produced in this report are shown both as crude mortality rates as well as after ‘stabilisation & adjustment’. This method of adjustment takes into account the effects of chance variation and 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 are presented compared to the UK average as the benchmark and those whose stabilised & adjusted rates are more than 10% above this figure have been highlighted.

This process is most reliable when used for large organisations rather than individual providers and hence the data for a variety of organisational structures have been reported.

**Historical Perspective**

The information that forms the basis of Section 1.5 of the report is from national registration systems (the ONS Child Mortality Statistics, GRO and NISRA). The mortality trends are broadly encouraging with a decline in rates of stillbirth and neonatal death. However the lack of consistency and detail in reporting means the data are difficult to interpret with confidence as the following might be responsible for the observed fall:

3. Variation in the management of babies born at 22\textsuperscript{0} to 23\textsuperscript{6} weeks gestational age;
4. Changes to the professional advice regarding the certification of babies born at or after 24\textsuperscript{0} weeks gestational age believed to have died before 24\textsuperscript{0} weeks gestational age;

The effect of deaths due to lethal congenital anomalies is also unclear from these data; with particular localities often having increased rates from this cause because of local cultural or religious groupings who do not access termination of pregnancy, or national legislation in Northern Ireland.

**Stabilised & adjusted mortality**

The main findings of the report are represented in a combination of maps and tables showing both the crude and the stabilised & adjusted mortality data for stillbirths, neonatal deaths and extended perinatal deaths (stillbirth and neonatal deaths combined). Babies born at less than 24\textsuperscript{0} weeks gestational age have been excluded. The data in the main report are shown for the relevant commissioning and service delivery organisations with deaths analysed based on the mother’s address at the time the death occurred. There are separate maps for stillbirths, neonatal deaths and extended perinatal deaths and 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 size of population covered by the particular organisation and the colour represents the comparison to the appropriate UK 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 the UK average
- Yellow: ● - up to 10% lower than the UK average
- Amber: ● - up to 10% higher than the UK average
- Red: ● - more than 10% higher than the UK average

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

| Clinical Commissioning Group (CCG) | Total births | Mortality rate per 1,000 births * | | | | |
|---|---|---|---|---|---|---|---|---|---|
| | | Mortality rate per 1,000 births * | | | | | |
| | | Stillbirth † | Neonatal ‡ | Extended perinatal † | | | | |
| | | Crude | Stabilised & adjusted | Crude | Stabilised & adjusted | Crude | Stabilised & adjusted | |
| Dorset | 7,516 | 2.13 | 3.99 | (3.28 to 3.95) | 1.33 | 1.60 | (1.24 to 1.84) | 3.46 | 5.33 | (4.14 to 6.73) |
| North, East, West Devon | 9,047 | 3.87 | 4.23 | (3.98 to 4.35) | 1.66 | 1.93 | (1.85 to 2.27) | 5.53 | 6.16 | (5.53 to 6.99) |
| Somerset | 5,455 | 2.02 | 4.03 | (3.61 to 4.43) | 1.65 | 1.83 | (1.77 to 2.49) | 3.67 | 5.57 | (4.67 to 6.38) |

It would be helpful for all relevant stakeholders to consider the appropriate benchmark for these data (which may well be lower than the current choice of UK average). However, for those organisations currently falling above or close to the ‘red band’ a more detailed local review is recommended to assess the deaths that were potentially avoidable or local factors that might explain the high rate.
Key Findings

5. There were 4,722 extended perinatal deaths (3,286 stillbirths and 1,436 neonatal deaths) occurring in the UK to babies born at 24+0 weeks gestational age or greater in 2013 (excluding terminations of pregnancy). The extended perinatal mortality rate was 6.0 per 1,000 total births, comprising 4.2 stillbirths per 1,000 total births and 1.8 neonatal deaths per 1,000 live births.*

6. Even after accounting for variation due to the number of births and adjustment for case-mix differences significant variation in rates of extended perinatal mortality across the UK persists. Amongst organisations responsible for commissioning care, stabilised & adjusted rates varied from 5.4 to 7.1 per 1,000 total births.*

7. The analysis of the mortality associated with the 2013 birth cohort has identified particular areas in the UK where more detailed local review of stillbirth and neonatal death rates is required. In future years, with more consistent data entry, areas with high mortality rates and the nature of this excess mortality will be identified with greater accuracy and reported by MBRRACE-UK.

8. 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. Babies of Black or Black British and Asian or Asian British ethnicity had the highest risk of extended perinatal mortality with rates of 9.8 and 8.8 per 1,000 total births respectively. Both these findings show that inequalities in perinatal outcomes persist in the UK.

9. Engagement of Trusts and Health Boards in the process of reporting data on stillbirths and neonatal deaths was inconsistent. Some clearly had established structures of good practice to monitor and review such deaths and report data to MBRRACE-UK in a timely fashion. Others appeared to have no such systems in place and only reported data after multiple requests. In some cases this occurred over one year after the death even when there were no outside factors (such as a Coroner or Procurator Fiscal inquest) that might have prevented access to some of the necessary information.

10. There are systematic differences in how clinicians certify babies born at 22+0 to 23+6 weeks gestational age with, for example, the percentage of neonatal deaths who were born at this early gestation varying from 11% to 28% across Operational Delivery Networks in England. Such variation in practice can have a significant impact on families’ experiences of access to maternity leave, support services and benefits.

11. The incomplete reporting of late fetal losses at 22+0 to 23+6 weeks gestational age to MBRRACE-UK by care providers prevents robust estimation of neonatal and extended perinatal mortality rates based on standard international criteria as recommended by the World Health Organization (all births from 22+0 weeks gestational age).

12. Inconsistency in the registration of intrauterine deaths prior to 24+0 weeks but who only deliver after 24+0 weeks of gestational age has the potential to have a major influence on national routine statistics. These effects will only be fully accounted for by Trusts and Health Boards engaging with the MBRRACE-UK data collection and reporting all these deaths.

* Since these rates exclude deaths to births at less than 24+0 weeks gestational age, they are not necessarily directly comparable to other previously published data.
Recommendations

1. All organisations which have been identified as having a stabilised & adjusted stillbirth, neonatal or extended perinatal mortality rate that fall in the red band should conduct a local review in order to check their data and to identify factors which might be responsible for their reported high stabilised & adjusted mortality rate. (Page 47 of the main report)

2. Organisations whose stabilised & adjusted stillbirth, neonatal or extended perinatal mortality rate fall within the amber band should similarly consider carrying out a local review. (Page 47 of the main report)

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 specialities should establish national aspirational targets for rates of stillbirths, neonatal deaths, and extended perinatal deaths against which all services can be assessed in future. This could be based on a stepwise approach working towards rates achieved by the current best performing countries in Europe. (Page 15 of the main report)

4. Units should ensure that a post-mortem examination is offered in all cases of stillbirth and neonatal death in order to improve future pregnancy counselling of parents. (Page 69 of the main report)

5. In order that Trusts and Health Boards can comply with the recommendations arising from the Morecambe Bay Investigation, they should fully engage with the MBRRACE-UK data collection so as to ensure the “systematic recording and tracking of perinatal deaths”. (Page 11 of the main report)

6. In order that data are of the highest quality, Trusts and Health Boards must collaborate with each other in the provision of information to MBRRACE-UK about mothers and babies who change provider units during pregnancy and after delivery. (Page 11 of the main report)

7. It is essential that all Trusts and Health Boards provide data which are 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 by:
   f) Improving the provision of maternal data for neonatal deaths;
   g) Working closely with MBRRACE-UK to improve the classification of cause of death. (Page 66 of the main report)

8. All organisations responsible for maternity services should report to MBRRACE-UK all births between 22+0 and 23+6 weeks gestational age who do not survive the neonatal period. (Page 50 of the main report)