Perinatal Mortality Surveillance Report

UK Perinatal Deaths for Births from January to December 2014

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

Frequently Asked Questions
for healthcare professionals

1) Why does the number of stillbirths and neonatal deaths in the report not correspond with those recorded locally?

There are several reasons why the number of stillbirths and neonatal deaths given in your report might not be the same as that recorded locally:

a) ***Late fetal losses and neonatal deaths of babies born at less than 24 weeks gestational age have not been included.*** In order to be able to include them in future reports it is essential that Trusts and Health Boards report all fetal losses between 22^{+0} and 23^{+6} weeks gestational age.

b) Terminations of pregnancy at any gestational age have also been excluded from the report, although deaths due to all other causes (including congenital anomaly) *have* been included.

c) When reporting by Trust or Health Board, the report includes all neonatal deaths for babies who were born within that Trust or Health Board, irrespective of where they died. Therefore, it is possible that some of these deaths occurred outside of the organisation.

2) Why does the number of births in the report not correspond with those recorded locally?

There are several reasons why the number of births recorded in the MBRRACE-UK report might not be the same as the number recorded locally:

a) Babies born at less than 24 weeks gestational age and all terminations of pregnancy have been excluded from the report.

b) The number of births has been obtained from routinely collected data which is reliant on accurate reporting by the Trust or Health Board and, in some cases, by parents.

i. For England and Wales the information relating to births has been obtained by combining data from NHS Numbers for Babies (NN4B) and the Office for National Statistics (ONS) birth registration data.

ii. For Scotland all registered births in Scotland during 2014 were reported to MBRRACE-UK by Information Services Division (ISD) Scotland. However, full individual information on the characteristics of the mother and baby was not available for about 11% of the births in Scotland during 2014. This was because the Maternity Inpatient and Day Case dataset (SMR02) record had either not been submitted to ISD from the place of delivery or ISD had been unable to match the SMR02 record to the corresponding birth registration record. In

this 2014 MBRRACE-UK report, information on all births in Scotland has been included wherever possible and where possible the missing information has been imputed. MBRRACE-UK will continue to work with ISD to ensure that complete data is available in the future.

iii. Northern Ireland Maternal and Child Health (NIMACH) provided the data to MBRRACE-UK for babies born in Northern Ireland.

MBRRACE-UK relies on the accurate routine reporting of *all* births as this will affect the rates reported by MBRRACE-UK.

3) Why don't the crude mortality rates in the report correspond with our local mortality rates?

The crude mortality rates in the report are unlikely to be exactly the same as any locally reported rate due to the inclusion criteria used for deaths (see FAQ 1) and births (see FAQ 2) in the MBRRACE-UK report.

4) Are home births included in the report?

Yes, where home births and subsequent deaths have been reported and where the birth was attributable to an organisation from the routine data sources for each country. However, for Scotland we know that this data is under-recorded through SMR02 (maternity hospital records) and this might affect the rates reported by MBRRACE-UK.

5) Are deaths which occur in the hospice setting included in the report?

Yes, where deaths have been reported via routine data sources, or to MBRRACE-UK, these have been included in the report. We would ask that all such deaths are reported via the MBRRACE-UK reporting system by the referring Trust or Health Board. A facility to attribute the place of death to a hospice has recently been included in the report form. If the list does not include your local hospice please let the MBRRACE-UK team know and we will add it to the list.

6) Why are deaths of babies who die as a result of a congenital anomaly included in the report?

The aim of MBRRACE-UK is to provide insight into the variations in perinatal mortality that do not result from differences in rates of congenital anomalies, as there is differences in the way that pregnancies affected by a congenital anomaly are managed across the UK. Local cultural and religious sensitivities which discourage terminations of pregnancy, and differences in the law in Northern Ireland, may have a significant impact on the mortality rates for some areas. However, we do not believe that the information available on the cause of death for births in 2014 is sufficiently robust to be able to reliably identify all deaths due to congenital anomaly.

We have been working with reporters to improve the coding of cause of death using the CODAC classification system and will look to include this information in the MBRRACE-UK reports as soon as it is sufficiently reliable.

7) Why are deaths of babies who die at 22 or 23 weeks gestational age not included in the report?

MBRRACE-UK aims to report all deaths from 22 weeks gestational age onwards which would allow direct comparisons to be made with other European countries. However there is currently no legal requirement in the UK for the registration of babies born before 24 weeks gestational age who show no signs of life at birth (late fetal losses). Consequently it is difficult to ensure that all of these deaths have been reported to MBRRACE-UK. While we recognise reporting of these deaths has significantly improved since 2013, we would encourage all UK maternity units to implement a systematic process to ensure these deaths are reported so that it is then possible to include them in future reports.

8) Why are neonatal death rates for Trusts and Health Boards reported by place of birth rather than place of death?

In order to calculate mortality rates, it is necessary to have information for all births (as the denominator of the rate). As information for all births is only available by place of birth, the rates of neonatal deaths need to be reported in this way.

However, we believe that reporting by place of birth provides important information on the care pathways for those babies born within an organisation.

9) What about post-mortem rates?

The data reported to MBRRACE-UK for births in 2014 indicates whether a post-mortem examination was offered or consented to but not whether a post-mortem took place. In December 2015, additional questions were added to the MBRRACE-UK case report form: “Was a post mortem undertaken?” and “Was a mortality review undertaken for this case?”. The responses to these questions will be included in the MBRRACE-UK Perinatal Surveillance report for births in 2016.

10) What other than quality of care might explain a high mortality rate?

This may be due to random variation in annual mortality rates, the effect of the proportion of mothers who for legal, cultural, or religious reasons choose to carry babies affected by severe congenital anomalies to term, or a higher than average number of women with high risk pregnancies giving birth to babies within an organisation.

11) What do I need to do if my data is categorised as "red"?

The MBRRACE-UK Perinatal Mortality Surveillance Report (May 2016) recommends:

> *"All organisations identified as having a stabilised & adjusted 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 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."*

12) How is the cause of death attributed in the report?

The primary categories of the 'Cause Of Death & Associated Conditions' (CODAC) system of death classification are used to list the cause of death for cases reported to MBRRACE-UK. Further information relating to the CODAC classification system can be found at: http://www.ncbi.nlm.nih.gov/pubmed/19515228

13) How were the comparator groups defined?

The comparator groups were created in order to enable comparisons between Trusts and Health Boards which are similar in terms of the proportion of mothers with high risk pregnancies who give birth in their hospitals. Since the mortality rates are presented by the place of birth (irrespective of where the death occurred) the aim was to group organisations by characteristics which would lead to mothers with high risk pregnancies giving birth there, either through booking or antenatal transfer. It was felt that the availability of neonatal surgical expertise and a Level 3 Neonatal Intensive Care Unit (BAPM definition) are important factors together with the number of deliveries within the organisation.

14) How were the Trusts and Health Boards allocated to a comparator group?

The Operational Delivery Networks in England, AWPS in Wales, ISD in Scotland and NIMACH in Northern Ireland provided information on the highest level of neonatal care provision and the availability of neonatal surgery within each Trust and Health Board. The number of babies delivered each year was obtained using routine birth registration data.

15) What are the average mortality rates for each of the comparator groups?

The average mortality rates for the UK and the comparator groups are shown in the table below.

	Mortality rate per 1,000 births[§]		
	Stillbirth[†]	**Neonatal[‡]**	**Extended perinatal[†]**
UK average	**4.16**	**1.77**	**5.92**
Level 3 NICU & neonatal surgery	4.60	2.73	7.31
Level 3 NICU	4.98	1.97	6.94
4,000 or more births	3.83	1.19	5.02
2,000 to 3,999 births	3.56	1.33	4.88
Under 2,000 births	3.23	0.95	4.18

† per 1,000 total births
‡ per 1,000 live births
[§] excluding terminations of pregnancy and births <24^{+0} weeks gestational age
Data sources: MBRRACE-UK, NN4B, ONS, NRS, ISD, NIMATS, States of Guernsey, States of Jersey
Note: different laws exist in Northern Ireland for the termination of pregnancy

16) How do we ensure that all deaths are reported?

Stillbirths and neonatal deaths reported to MBRRACE-UK were compared to registered deaths (ONS for England and Wales, NRS for Scotland) in order to identify unreported deaths. A combination of deterministic and probabilistic matching methods is used to match registered deaths from these sources with those reported to MBRRACE-UK. For England, Wales and Scotland this is based on factors including the mother's given name, mother's family name, postcode of residence, Trust or Health Board of birth, baby's NHS number (where available), and gestational age at delivery.

Potential missing cases are listed within the MBRRACE-UK online reporting system and registered reporters are able to generate reports and verify eligible cases. The NIMACH office confirmed full data validation for Northern Ireland.

17) Why are the mortality rates "stabilised & adjusted"?

While the crude mortality rates offer a snapshot of the mortality for a single year, they are subject to random variation and might not be a reliable estimate of the underlying (long-term) mortality. The **stabilisation** of the mortality rates is a statistical method which allows for the effect of random variation and produces estimated mortality rates which are closer to the underlying mortality rate.

The mortality rates are also **adjusted** to account for key factors which are known to increase the risk of perinatal mortality. The extent of the adjustment is limited to only those factors that are collected for all births across the whole 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).

Thus, stabilised & adjusted mortality rates have been used in order to provide more reliable estimates of the mortality rates and avoid unfair comparisons across organisations by taking into account the number of high risk pregnancies and the effect of chance variation.