

# Frequently asked questions

## Mortality rates

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### 1) Why doesn't the number of stillbirths and neonatal deaths in the report 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 most of the tables of the report.** This is due to the inconsistent reporting of late fetal losses to MBRRACE-UK by some Trusts and Health Boards in 2013. 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<sup>+0</sup> and 23<sup>+6</sup> 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) The report includes all neonatal deaths for babies who were born within your Trust or Health Board irrespective of where they died. Therefore, it is possible that some of these deaths occurred outside of your organisation: information about this is shown on page 6 of the report.

### 2) Why doesn't the number of births in the report correspond with those recorded locally?

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

- a) Babies born at less than 24 weeks gestational age and all terminations of pregnancy have been excluded from this report.
- b) The number of births for each Trust and Health Board has been obtained from routinely collected data which is reliant on accurate reporting by your organisation 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) In Scotland the data was obtained from National Records of Scotland (NRS) and Information Services Division (ISD). However, it is known that a small percentage of births are not available from SMR02 (maternity hospital records), with home births especially known to be under-recorded.

(see <http://www.isdscotland.org/Health-Topics/Maternity-and-Births/Births/Background.asp>).

- iii) Northern Ireland Maternity 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 your 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) Why don't the mortality rates in the report correspond with the mortality rates in the MBRRACE-UK Perinatal Mortality Surveillance Report (June 2015)?**

For Trusts and Health Boards in Scotland, Wales and Northern Ireland the **crude** mortality rates in your report should match those in Table 5 of the MBRRACE-UK Perinatal Mortality Surveillance Report launched in June 2015, except where minor updates to the data have been reported to us since the production of the earlier report. However, the **stabilised & adjusted** rates in your new report are likely to be different from those reported previously as they have been stabilised to the average mortality rates of Trusts and Health Boards similar to yours (see FAQ 16).

In Table 5 of the MBRRACE-UK Perinatal Mortality Surveillance Report launched in June 2015 mortality rates in England for the place of birth were given by Operational Delivery Networks (ODNs) and not individual Trusts.

### **5) Are home births included in the report?**

Yes, home births have been reported where the birth was attributable to your Trust or Health Board from the routine data sources for your country. However, for Scotland it is known that home births are under-recorded through SMR02 (maternity hospital records) and this might affect the rates reported by MBRRACE-UK.

### **6) Why are neonatal death rates 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 your organisation. There is information on page 6 of the report outlining whether the deaths occurred within your Trust or Health Board, or whether the baby *died elsewhere*.

## 7) Why doesn't the number of deaths for which a post-mortem was conducted correspond with our local rates?

This is likely to be because the data reported to MBRRACE-UK indicates whether a post-mortem examination was offered or consented to and not whether the post-mortem took place. Please note the report also differentiates between whether post mortem was offered for babies who were born in your organisation and subsequently died there and those who were born in your organisation and died elsewhere.

## 8) What other than quality of care might explain the high mortality rate in my Trust or Health Board?

This may be due to random variation in annual mortality rates, the effect of concentrations 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 delivering babies within your organisation.

## 9) What do I need to do if my data is categorised as “red” or “amber”?

The *MBRRACE-UK Perinatal Mortality Surveillance Report* (June 2015) recommends:

*“For those whose mortality rates fall into the red band ● a detailed local review is indicated to try to assess the deaths that were potentially avoidable or to investigate local factors that might explain the high rate. For those whose mortality rates fall in to the amber band ● similar reviews should also be carried out.”*

The Lead Reporter for your organisation is able to download all of the deaths reported to MBRRACE-UK via the MBRRACE-UK data collection system by downloading the ‘Trust/Health Board Overview Report’.

## 10) How can we find out the mortality rates of other Trusts and Health Boards?

On the **16<sup>th</sup> December 2015**, a report of the crude and the stabilised & adjusted perinatal mortality rates for all Trusts and Health Boards in the UK will be made publicly available via the MBRRACE-UK web page.

# Data collection

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## 11) How is socioeconomic deprivation calculated for babies born within my organisation?

For all babies born in your organisation, we link the postcode of residence of the mother to the *Children in Low-Income Families Local Measure* to assess the level of socioeconomic deprivation. This measure is based on the proportion of children living in families in receipt of out-of-work (means-tested) benefits or in receipt of tax credits where their reported income is less than 60 per cent of UK

median income. We allocate each birth to a socioeconomic deprivation quintile which range from the least deprived fifth of births to the most deprived fifth.

## 12) How can I find out the national distribution of socioeconomic deprivation, ethnicity or gestational age?

You will find this information contained in the PowerPoint slide set which accompanies the report.

## 13) How is the ethnicity designated for babies born within my organisation?

The MBRRACE-UK report relies on the accurate coding of ethnicity in routinely reported data (NN4B, ONS, NRS, ISD, NIMATS) and uses the information from these sources when designating ethnicity for babies born within your organisation. Since different classifications of ethnicity are used in the different countries of the UK, we assign them to groupings that can be defined across the UK.

## 14) 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 by your organisation. Further information relating to the CODAC classification system can be found at: <http://www.ncbi.nlm.nih.gov/pubmed/19515228>

## 15) Why are key data items missing for deaths occurring within our organisation?

Please make any improvements you can to your current and prospective data collection if you have less than 100% completeness for the data reported to MBRRACE-UK by your organisation..

Incomplete data would usually only be expected in the following circumstances:

- a) The mother's obstetric and medical history is withheld for reasons of confidentiality e.g. when the death is a result of a termination of pregnancy.
- b) The mother is a foreign national with limited or no English and no interpreting services were available.
- c) A case has been assigned to another hospital for additional data to be added (e.g. the mother's booking details) before the case can be validated and closed. Please let us know if there is a delay in the case being completed and returned and we will try to provide additional local contacts to help you resolve and close the case.
- d) The mother presented as a late booking for antenatal care, or did not attend for antenatal care. **Please note, the percentages reported for incomplete data in the 'Booking information and antenatal care' section do not include those women who chose not to engage with maternity services.** Please use the "unknown" option when reporting this information.
- e) The cause of death section is incomplete and awaiting results of a post-mortem examination or Coroner's inquest. Please report the most likely cause of death and record that a "PM result is awaited" in the box which appears when you close and validate the case. You are then able to use the "re-open a case" option once this becomes available.

# Comparison with other organisations

## 16) 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.

## 17) 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.

## 18) 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. The UK rates differ slightly from those reported in the national MBRRACE-UK perinatal mortality report launched in June 2015 because of the omission of a small number of births that could not be allocated to a Trust or Health Board.

	Mortality rate per 1,000 births		
	Stillbirth <sup>†</sup>	Neonatal <sup>‡</sup>	Extended perinatal <sup>†</sup>
<b>UK average</b>	4.23	1.88	6.15
<b>Level 3 NICU &amp; neonatal surgery</b>	4.69	2.49	7.22
<b>Level 3 NICU</b>	4.75	2.09	6.88
<b>4,000 or more births</b>	3.95	1.39	5.35
<b>2,000 to 3,999 births</b>	3.48	1.38	4.88
<b>Under 2,000 births</b>	3.31	1.14	4.47

<sup>†</sup> per 1,000 total births; <sup>‡</sup> per 1,000 live births

## 19) What do I do if I feel our Trust or Health Board has been inappropriately allocated to a comparator group?

If you feel that your organisation has been allocated to the wrong comparator group, please contact the MBRRACE-UK team: Email [mbrrace-uk@npeu.ox.ac.uk](mailto:mbrrace-uk@npeu.ox.ac.uk) and let us know why you feel your organisation is in the wrong group.

# Data analysis

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## 20) How do the MBRRACE-UK team 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.

## 21) 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 for a Trust or Health Board. 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 for any Trust or Health Board.

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. For further detailed information please see pages **18-19** and **95-96** of the Perinatal Mortality Surveillance Report (June 2015) <https://www.npeu.ox.ac.uk/mbrance-uk/reports>