How data can help us to reduce infant mortality - MBRRACE-UK

Lucy Smith
HQIP Maternal, Newborn and Infant Clinical Outcome Review Programme

• Surveillance of all stillbirths and neonatal deaths
• Confidential enquiries of a rolling programme of infant mortality and serious infant morbidity

• Surveillance of all maternal deaths (to 1 year from the end of pregnancy)
• Confidential enquiries of all maternal deaths (to 1 year from the end of pregnancy)
• Confidential enquiries of a rolling programme of serious maternal morbidity
MBRRACE-UK data collection

- Stillbirths (from 24⁺⁰ weeks)
- Neonatal deaths (from 20⁺⁰ weeks)
- Late fetal losses (22⁺⁰ to 23⁺⁶ weeks)

646 MBRRACE-UK Reporters

374 Lead Reporters
Denominator & validation data

HSCIC NN4B / PDS
- NIMATS births
- NIMATS deaths
- NIMATS inpatient data
- ISD – SMR02

ONS births
- NRS births
- NRS deaths

States of Jersey births
- States of Jersey deaths

States of Guernsey births
- States of Guernsey deaths

NIMATS inpatient data

782,311 births
5,623 deaths of babies
Factors affecting perinatal mortality

• Denominator data available for all births
  – Mother’s age, deprivation
  – Baby’s ethnicity, gestation, sex, multiplicity, birthweight

• Detailed data available for deaths
  – Mother’s demographics, previous medical history, antenatal care, labour and birth
  – Baby’s outcomes, cause of death, post-mortem
Out of over 780,000 births in 2014...

5,623 registered deaths of babies before, during or within the first 4 weeks of birth
Out of over 780,000 births in 2014...

- 5,623 registered deaths of babies before, during or within the first 4 weeks of birth

  - 4,633 deaths of babies born from 24 weeks of pregnancy
    - 3,252 stillbirths
    - 1,381 neonatal deaths

  6 deaths for every 1,000 births

Excludes...

- Births before 24 weeks of gestation.
- Terminations of pregnancy

Includes

- Deaths due to congenital anomalies
MBRRACE-UK Aims

For parents and health professionals:

– To quantify the burden of mortality in the UK and allow international comparisons
– To identify risk factors for perinatal mortality
– To compare organisations providing care in the UK

For healthcare providers

– To provide information to health care providers to facilitate improvements in care
– To make recommendations for improving care
– To contribute to the development of standards and guidance
Table 2: Stillbirth, neonatal, and extended perinatal mortality rates (95% confidence intervals (CIs)) by country of residence: United Kingdom and Crown Dependencies, for births in 2014

<table>
<thead>
<tr>
<th>Rate per 1,000 births*</th>
<th>UK^</th>
<th>England</th>
<th>Scotland</th>
<th>Wales</th>
<th>Northern Ireland°</th>
<th>Crown Dependencies</th>
</tr>
</thead>
<tbody>
<tr>
<td>Stillbirths†</td>
<td>4.16 (4.01 to 4.30)</td>
<td>4.19 (4.04 to 4.35)</td>
<td>3.69 (3.19 to 4.19)</td>
<td>4.71 (3.98 to 5.44)</td>
<td>3.76 (2.99 to 4.52)</td>
<td>1.24 (0.00 to 2.64)</td>
</tr>
<tr>
<td>Antepartum†</td>
<td>3.65 (3.51 to 3.78)</td>
<td>3.69 (3.55 to 3.84)</td>
<td>3.23 (2.76 to 3.70)</td>
<td>3.85 (3.19 to 4.51)</td>
<td>3.35 (2.62 to 4.07)</td>
<td>1.24 (0.00 to 2.64)</td>
</tr>
<tr>
<td>Intrapartum†</td>
<td>0.35 (0.31 to 0.39)</td>
<td>0.35 (0.30 to 0.39)</td>
<td>0.30 (0.16 to 0.44)</td>
<td>0.68 (0.40 to 0.96)</td>
<td>0.20 (0.03 to 0.38)</td>
<td>0.00 (0.00 to 1.24)</td>
</tr>
<tr>
<td>Unknown timing†</td>
<td>0.16 (0.13 to 0.19)</td>
<td>0.16 (0.13 to 0.19)</td>
<td>0.16 (0.06 to 0.26)</td>
<td>0.18 (0.04 to 0.32)</td>
<td>0.20 (0.03 to 0.38)</td>
<td>0.00 (0.00 to 1.24)</td>
</tr>
<tr>
<td>Neonatal deaths†</td>
<td>1.77 (1.68 to 1.87)</td>
<td>1.73 (1.63 to 1.83)</td>
<td>1.86 (1.51 to 2.22)</td>
<td>1.67 (1.23 to 2.10)</td>
<td>2.99 (2.31 to 3.68)</td>
<td>1.24 (0.00 to 2.65)</td>
</tr>
<tr>
<td>Early neonatal deaths‡</td>
<td>1.23 (1.15 to 1.30)</td>
<td>1.17 (1.09 to 1.26)</td>
<td>1.35 (1.04 to 1.65)</td>
<td>1.31 (0.92 to 1.70)</td>
<td>2.25 (1.66 to 2.85)</td>
<td>1.24 (0.00 to 2.65)</td>
</tr>
<tr>
<td>Late neonatal deaths‡</td>
<td>0.55 (0.49 to 0.60)</td>
<td>0.55 (0.50 to 0.61)</td>
<td>0.51 (0.33 to 0.70)</td>
<td>0.36 (0.16 to 0.56)</td>
<td>0.74 (0.40 to 1.08)</td>
<td>0.00 (0.00 to 1.24)</td>
</tr>
<tr>
<td>Perinatal deaths‡</td>
<td>5.38 (5.22 to 5.54)</td>
<td>5.36 (5.19 to 5.54)</td>
<td>5.03 (4.45 to 5.62)</td>
<td>6.01 (5.19 to 6.84)</td>
<td>6.00 (5.03 to 6.97)</td>
<td>2.48 (0.50 to 4.46)</td>
</tr>
<tr>
<td>Extended perinatal deaths‡</td>
<td>5.92 (5.75 to 6.09)</td>
<td>5.91 (5.73 to 6.10)</td>
<td>5.55 (4.93 to 6.16)</td>
<td>6.37 (5.52 to 7.22)</td>
<td>6.74 (5.71 to 7.76)</td>
<td>2.48 (0.50 to 4.46)</td>
</tr>
</tbody>
</table>

* per 1,000 total births
† per 1,000 live births
* excluding terminations of pregnancy and births <24° weeks gestational age
What risks do we know about babies who die before, during or shortly after birth?

- 3x higher risk of twins
- 80% higher for Black or Black British babies
- 60% higher for Asian or Asian British babies
- 60% higher for mothers aged 40 and over
- 50% higher for mothers living in poverty
- 30% higher for teenage mothers
What do we know about why babies die?

Causes of stillbirth

- 46% unknown causes
- 22% placental problems
- 6% congenital anomalies
- 6% complications during labour
- 5% complications before labour
- 4% mother’s health
- 4% umbilical cord
- 4% not reported infections
- 3% reported infections
What do we know about why babies die?

Causes of neonatal death

- Complications after birth: 31%
- Congenital anomalies: 28%
- Born extremely early: 13%
- Infections: 7%
- Complications before labour: 5%
- Complications during labour: 5%
- Unknown causes: 5%
- Not reported: 4%
- Placental problems: 2%
Organisations reported

1. National data - based on mother’s birth address
2. Commissioning organisations - based on mother’s birth address
3. “Local Authorities” - based on mother’s birth address
4. Trusts and Boards - based on where birth occurred
5. Neonatal Networks - based on where birth occurred
How are the mortality rates calculated?

• **Crude mortality rate**
  Number of deaths that occurred for every 1,000 births in 2014

• **Stabilised & adjusted mortality rate**
  Estimated 'underlying' rate taking into account differences in risk and chance variation
Stabilisation

• Take into account the lack of data

• Take into account unmeasured differences

• “How much evidence is there that the mortality rate of any organisation is different from the average rate?”
Adjustment for case-mix

Take into account reported characteristics:

- Mother’s age
- Baby’s ethnicity
- Baby’s sex
- Child poverty index
- Multiple birth

Data available for **ALL** births
Classification of mortality rates

- **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
Trusts and Boards - based on where birth occurred
Comparator groups

Group ‘similar’ Trusts and Health Boards

1. Level 3 NICU & neonatal surgery
2. Level 3 NICU
3. 4,000 or more births annually
4. 2,000 to 3,999 births annually
5. Fewer than 2,000 births annually
Figure 14: Crude extended perinatal mortality rates by NHS Trust (England), Health Board (Scotland and Wales), Health and Social Care Trust (Northern Ireland), and Crown Dependency based on place of birth: United Kingdom and Crown Dependencies, for births in 2014.

Crude extended perinatal mortality rates:
- Rate suppressed due to small numbers
- More than 10% lower than group average
- Up to 10% lower than group average
- More than 10% higher than group average
- Up to 10% higher than group average

The size of the symbol is proportionate to the number of births.

Figure 15: Stabilised & adjusted extended perinatal mortality rates by NHS Trust (England), Health Board (Scotland and Wales), Health and Social Care Trust (Northern Ireland), and Crown Dependency based on place of birth: United Kingdom and Crown Dependencies, for births in 2014.

Stabilised and adjusted extended perinatal mortality rates:
- Not calculated due to unavailable data
- More than 10% lower than group average
- Up to 10% lower than group average
- More than 10% higher than group average
- Up to 10% higher than group average

The size of the symbol is proportionate to the number of births.

Notes:
- Excluding terminations of pregnancy and births less than 24 weeks gestational age.
- Different laws exist in Northern Ireland for the termination of pregnancy.

Sources: MBRRACE-UK, NNAS, ONS, NRS, SD, NIMATS, States of Guernsey, States of Jersey.
What do the colours really mean?

• They are not definitive measures of quality of care

• They are robust estimates of rates of mortality given available data

• 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 of data quality and care provision to establish whether there are lessons to be learned to improve the quality of care provision within their organisation.
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Confidential Enquiries

Congenital diaphragmatic hernia
- published December 2014

Term, singleton, normally formed antepartum stillbirth
- published November 2015

Intrapartum stillbirths and intrapartum related neonatal deaths
- to be published November 2017

Multiple births ending in stillbirth or neonatal death
- to be published November 2019
Opportunities for getting involved

• MBRRACE-UK collaborative team – Sands
• Participate in stakeholder events
• Authorship of lay summary reports
• Submission of topics for Confidential Enquiries

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AND

• Reporters
• Collaborators
• Data providers
• Lay & Professional stakeholders
• Topic Expert Group & panel members
• Main & lay report writers