Child Death Overview Panel: Neonatal Themed Panels Briefing October 2021

1. Introduction

Since September 2020, the HIPS CDOP has conducted three Neonatal Themed Panels. The statutory guidance suggests that themed panels can enable appropriate professional experts to be present to inform discussions and easier identification of themes.[1]

Holding these themed panels has enabled constructive discussion regarding potential modifiable factors and mapping of what initiatives are already underway across Maternity Services. There is recognition of parallel investigations undertaken for neonatal deaths, including the Healthcare Safety Investigation Branch, HSIB, which had representatives present at the September 2021 Panel (see Appendix 1).

2. Context of Neonatal deaths in the UK

2.1 National findings

Every year MBRRACE-UK produces a "Perinatal Mortality Surveillance" report which provides rates for stillbirths and neonatal deaths, and also for these deaths combined; known as 'extended perinatal deaths'[2]. A neonatal death is a baby born at any gestation who lives, even briefly, but dies within 4 weeks of birth.

MBRRACE-UK (2021)[3] identified that 47% of neonatal deaths were caused by extreme prematurity or incompatibility with life due to congenital anomalies. The highest rates were those combining the following factors:

- Black or Asian;
- Mother under 25 or over 35 years;
- Living in the most deprived areas.

MBRRACE-UK (2021)[4] reported that there were 1,495 (from 22 weeks) neonatal deaths in the UK in 2019. This is a 12% reduction since 2013 (770 deaths).

The National Child Mortality Database (NCMD) Annual Report 2019/2020 notes that there were approximately 20% more neonatal deaths registered than reported to the NCMD.[5]
For perinatal/neonatal events within child death reviews:

- 80% were immaturity/prematurity related;
- 13% were related to perinatal asphyxia;
- 5% were due to perinatally acquired infection.

The vast majority (77%) of deaths in children born after 37 weeks gestation were due to perinatal asphyxia or linked to reports of out of hospital delivery, placental abnormalities and antepartum haemorrhage.

The NCMD annual report stated that the main modifiable factor for neonatal deaths was noted to be in the social environment: smoking by a parent or carer, raised maternal BMI during

[1] https://assets.publishing.service.gov.uk/government/uploads/system/uploads/attachment_data/file/859302/child-death-review-statutory-and-operational-guidance-england.pdf
[2] https://www.npeu.ox.ac.uk/assets/downloads/mbrrace-uk/reports/perinatal-surveillance-report-2018/MBRRACE-UK_Perinatal_Surveillance_Report_2018_-_summary.pdf
[3] https://www.npeu.ox.ac.uk/assets/downloads/mbrrace-uk/reports/perinatal-surveillance-report-2019/MBRRACE-UK_Perinatal_Surveillance_Report_2019_-_infographic_summary.pdf
[4] https://www.npeu.ox.ac.uk/assets/downloads/mbrrace-uk/reports/perinatal-surveillance-report-2019/MBRRACE-UK_Perinatal_Surveillance_Report_2019_-_infographic_summary.pdf
[5] https://www.ncmd.info/wp-content/uploads/2021/06/NCMD_2nd_Annual_Report_June-2021_web-FINAL.pdf

pregnancy, substance and/or alcohol misuse by a parent or carer, domestic violence, challenges with access to services and unbooked pregnancies.[6]

2.2 National recommendations

MBRRACE-UK (2021)[7] emphasised the need to:

- Develop research and interventions to reduce inequalities between women, focusing on preventing deaths for those mothers most at risk of their baby dying because of factors associated with ethnicity, age and social deprivation.
- Improve implementation of existing prevention programmes, focusing on research and prevention of preterm birth, particularly extremely pre-term birth.
- Use the MBRRACE-UK guidance to assess signs of life in babies born before 24 weeks.
- Improve access and support for women aged under 20 or over 35, to ensure they are empowered with the right contraception advice and can make informed decisions around pregnancy risks.
- Make information about congenital anomalies a part of all routine pre-conception care for women who may be at risk of this outcome when they become pregnant.

MBRRACE-UK (2021)[8] identified the following areas for improvement:

- Support poorer women throughout pregnancy, childbirth and early parenting, by ensuring the different agencies who support them, from social care to health services, work together.
- Understand what support women from Black and Asian communities specifically need around conception, pregnancy and childbirth.
- Ensure an examination of the placenta is carried out by a specialist pathologist for every baby who dies in a neonatal unit.

3. Neonatal deaths across HIPS as reviewed by the CDOP in September 2021

3.1 Getting the language right: communication and expectations of parents and their understanding

The Panel considered how professionals talk to parents and find the right way of signposting parents to counselling, when declined antenatally. Professionals should consider whether the parents have fully comprehended the risks and the outcome for their baby. This links to the findings of other HIPS Panels in relation to the experience of parents.

Learning (from previous Panels)**: Empowering parents**

- To make their own choices regarding the progress of their pregnancy can enable the parents to move forward in their bereavement journey
- Professionals work hard to have the conversations with parents to support them in accessing genetic testing. This can help parents to gain a greater understanding of the risks and to make informed decisions regarding further pregnancies
- The view of the panel was to encourage the promotion of the 'Ask 3 Questions' campaign within Maternity Services to support parents to consider their choices:
  - What are my options?
  - What are the pros and cons for each option?
  - What support is available to help me make a decision?

The Panel discussed the use of the Wessex Healthier Together website/app for parents and how population profiles can be monitored to identify localities where there could be more intensive preventative work.

[6] NCMD Annual Report pp. 38 [Online]
[7] https://www.npeu.ox.ac.uk/assets/downloads/mbrrace-uk/reports/perinatal-surveillance-report-2019/MBRRACE-UK_Perinatal_Surveillance_Report_2019_-_infographic_summary.pdf
[8] https://www.npeu.ox.ac.uk/assets/downloads/mbrrace-uk/reports/perinatal-surveillance-report-2019/MBRRACE-UK_Perinatal_Surveillance_Report_2019_-_infographic_summary.pdf

In previous Panels, there were some cases which caused concern due to parents potentially delaying accessing services because of the COVID-19 pandemic or how the services themselves were being delivered differently during this time for Maternity Services and in how they were able to meet with bereaved families.

As part of the September CDOP, there was a presentation by the Healthcare Safety Investigation Branch (Appendix 1). This highlighted the findings from reviews into deaths during COVID-19, including how deaths related whether issues were pre-existing, exacerbation during the pandemic, or specific to COVID-19. The themes covered guidance, risk management, telephone triage, interpretation services, work demands and neonatal resuscitation. These findings will be used to map learning from the Neonatal Panels.

3.2 Bereavement support across services

Previous panels have identified some strong bereavement support in Maternity Services, including how parents are supported through their decision making, for example, when it is known that the baby will not survive, some parents do not want to terminate the pregnancy and would prefer to deliver their baby.

However, care needs to be taken to ensure continuity and consistency of the support when a child is transferred shortly before death. This can have an impact on the quality of the bereavement support and the information for the local child death review.

3.3 Continuity of maternity carer and linkage to better outcomes

The Panel discussed how continuity of carer within maternity can be linked to better outcomes for both mother and baby. Where there are transfers of care, then teams should be mindful of the impact of changes on the family.

Transfer of care has been considered by previous Panels in relation to the timing of transfers and subsequent risk to the baby's wellbeing or delays in admission despite parents being in touch with the service.

The improvements noted were:

- Single point of contact for access to tertiary centres
- Use of BadgerNet to aid access to information and risk assessments

3.4 Promoting risks of smoking and obesity in pregnancy

Recurring themes of modifiable factors for neonatal deaths are parental smoking and maternal obesity during pregnancy. Although not direct causal factors for deaths, the Panel, as seen by the findings of the National Panel, are firmly of the view that these make the baby more vulnerable to issues that could cause their death. What is not clear to the Panel is how much parents are being warned about the risks before conception.

Previous Panels have discussed the need to continue to strengthen pre-conception education and counselling to support parents to fully understand the risk factors when there are issues in relation to the mother's wellbeing that could have an impact on the baby.

Areas for consideration within Population Health

- Consider role of Primary Care in raising awareness of the risks for women who are obese or who smoke
- How can the ICS support this work? Is there something the Primary Care Networks can work on for their local population?
- Take a wider family approach to inform the benefits of behaviour change for the future health of children

- Consider the need for engaging wider family members in neonatal units and interlinking with health visitors

3.5 Thermal care

The Panel has found that there have been cases throughout the last two years involving problems in how the thermal care of premature babies is managed. The Panel heard that there is guidance and measures in place to manage this, but services need to ensure that this is achieved appropriately.

4. Conclusion and action required by the HIPS system by April 2022

Themed Panels are helping to highlight the areas that need vital improvements and development, yet they also enable areas of good practice to be acknowledged.

The areas noted in the report(s) will continue to be scrutinised by the CDOP. The findings will inform the conclusions of the HIPS CDOP Annual Report 2020/2021 to enable assurance to be provided to the accountable bodies for the statutory child death review process and emphasise the further improvements needed within Maternity Services.

It is expected that this briefing will be shared widely across the system and that the strategic and operational groups involved in developing Maternity Services provide the CDOP with responses on actions undertaken based on the findings.

Nicola Brownjohn
Independent Chair of the HIPS CDOP
October 2021

Appendix 1


HSIB
HEALTHCARE SAFETY
INVESTIGATION BRANCH
HSIB CDOP presentation
28th September 2021
Dawn Worsnip, Maternity Investigator, South Central
Rachel Rees, Investigations Team Leader, South Central


About us
HSIB
HEALTHCARE SAFETY
INVESTIGATION BRANCH
Independent safety investigations in NHS-funded care
Do not apportion blame or liability
Focus on system-level (policy and regulatory) change
Professionalise the patient safety investigator role

Our approach

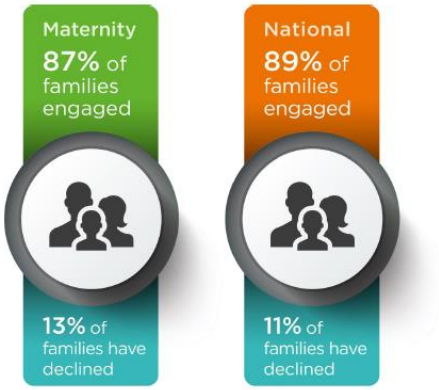
Wide ranging expertise from safety-critical industries

Multidisciplinary and inclusive teams; patient and family involvement

Focus on learning not blame to reduce further risk of harm

Transparent and collaborative to support learning

Patient, family and staff are central



Surveys to drive continuous improvement

Maternity

50 trusts & 300 staff responses

Staff survey ongoing. Next trust survey 2021

National

Survey in development for trusts and staff in 2021

HSIB's investigation programmes

National investigations programme	Maternity investigations programme
2016 Directions – core purpose of HSIB	**2018** Directions – additional specific programme
Diverse range of healthcare services and safety risks	Explicit focus on NHS maternity services in England
Criteria: we decide • scale of risk and harm • potential for learning to prevent future harm • impact on individuals and public confidence in the healthcare system	**Criteria: set for us** • RCOG Each Baby Counts programme • Direct maternal deaths • Indirect maternal deaths while pregnant or within 42 days of giving birth
Up to 30 investigations a year	Circa 1000 investigations a year
Do not replace local investigations	Replaces the local investigation
Recommendations made to healthcare and beyond	Recommendations made only to the trust
Reports published on HSIB website	Reports belong to the family and the trust

National investigations

48* reports published/completed

130 safety recommendations to **39** different organisations

99 safety observations

36 safety actions

*As of 30 April 2021

Recent publications:

Maternity investigations

2,163 investigations commenced

1,789* reports completed

*As of 31 July 2021

Working with all **125** Acute Trusts in **14** regions

11 NHS Ambulance Trusts

Recent publications:

HSIB Maternity Investigation Process

A Summarised 10 Step Guide for Families

STEP 01
- The hospital refers your case to HSIB as required to by Department of Health & Social Care
- The hospital informs you about HSIB and asks for your agreement to pass your contact details to us
- The hospital gives you our HSIB introduction card

STEP 02
- An investigator contacts you and explains more about our investigation process
- We ask for permission to access your data (your medical notes) and to process your personal data as part of the investigation (medical notes/interview).
- You discuss with the investigator how and to what extent you would like to be involved and contacted

STEP 03
- An initial meeting with investigators is planned with your agreement
- The investigation process is explained further, and you ask any questions you have
- We provide you with a family information leaflet
- We can give you information about additional support you may require
- You can change your mind at any time but this does not mean our investigation has to stop

STEP 04
- We arrange to interview you and other key family members about your experience
- We discuss with you the terms of reference of the investigation
- We revisit any support you may require
- (Steps 3 and 4 can happen at the same time if this is what you wish)

STEP 05
- Your investigators will interview key members of staff
- The investigators will seek expert clinical advice surrounding your experience
- Your investigators will keep you updated of the progress of the investigation

STEP 06
- Investigators will analyse findings
- Further clinical advice will be sought to review the progress of the investigation
- Your investigators will keep you updated to their progress

STEP 07
- A draft report will be prepared detailing what happened, any findings and recommendations
- The report will be will go through a comprehensive quality assurance process

STEP 08
- Draft report will be shared with the hospital
- The draft report will be shared with you and details explained
- Any details that you believe are inaccurate are discussed

STEP 09
- You are given your copy of the final report
- The final report is also given to the hospital
- We will discuss with you the opportunity of a three way meeting with the Trust to discuss with them any next steps. This will be led by the Trust.

STEP 10
- We ask you and your family for feedback on our investigation process
- The HSIB investigation concludes

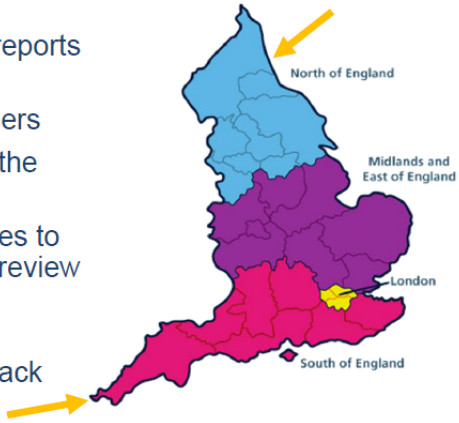
Maternity: Top 5 Recommendations

- Guidance
- Fetal Monitoring
- Clinical Oversight
- Clinical Assessment
- Escalation

- **283 reports have no safety recommendations**

Sharing learning from Maternity investigations

- National learning reports
- Collaboration with external stakeholders
- Engagement with the Coroners Service
- Feedback of themes to trusts at quarterly review meetings
- Collating regional themes and feedback



HSIB national learning reports

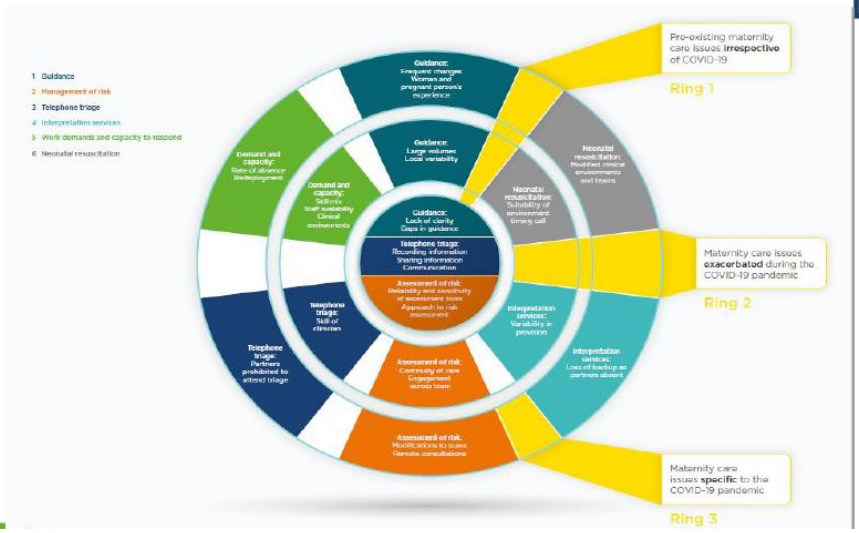
Publications to date:
- Severe brain injury, early neonatal death and intrapartum stillbirth associated with GBS
- Neonatal collapse alongside skin to skin contact
- Giving families a voice
- Delays to intrapartum care once fetal compromise is suspected
- Larger babies and shoulder dystocia
- Maternal death during the first wave of the COVID-19 pandemic
- Suitability of equipment for CTG monitoring
- Intrapartum intrauterine deaths during COVID-19

Future publications:
- **Early recognition of risk**
- **Handovers**
- **Cultural considerations**

NLR: Neonatal collapse alongside skin-to-skin contact

- A baby who is born apparently well, with good Apgar scores, can be safely laid skin-to-skin with the mother or parent and requires close observation in the first minutes after birth.
- Care should be taken to ensure that the baby's position is such that their airway remains clear and does not become obstructed.
- Always listen to parents and respond immediately to any concerns raised

NLR: Intrapartum intrauterine deaths during COVID-19



Discussion

- Sharing of information
- Working together
- Expectations