Perinatal Surveillance & Review Standard Operating Procedure

University Hospitals of Leicester NHS Trust

Trust Ref: C53/2024

Contents

1. Introduction and overarching policy/guideline

Review of care, when a baby dies, will be a routine part of maternity and neonatal care to provide answers for bereaved parents and families about what happened and why their baby died. Importantly, wider learning also comes from both individual and summarised review findings, which will be used to improve care and prevent future unintended outcomes and baby deaths. Since 2018, review has been conducted by Trusts in the UK for all eligible deaths using the national *Perinatal Mortality Review Tool* (PMRT). The PMRT was developed by a collaboration led by MBRRACE-UK and appointed by the *Healthcare Quality Improvement Partnership* (HQIP) to standardise and improve the quality of review for all babies regardless of the location of their birth or death.

Throughout this report, we use the terms 'women' and 'mothers' to refer to those who are pregnant and give birth. We acknowledge that not all people who are pregnant or give birth identify as women, and it is essential that evidence-based care for maternity, perinatal and postnatal health is inclusive.

This standard operating procedure (SOP) exists under the overarching UHL Policy for Learning from the Deaths of Patients Who Have Been in Our Care UHL Policy.pdf B4/2023

Background

There is a well-established requirement for maternity service providers to ensure that all qualifying perinatal mortality cases are reported to MBRRACE-UK within a specific time frame. Additionally, additional time frames are outlined within this SOP as essential for submitting further surveillance data to MBRRACE-UK a full multi-disciplinary review using the PMRT tool, and publishing of a final PMRT report. Such deaths are often subject to additional statutory or external review, such as that conducted through the coronial, Child Death Overview Panel (CDOP) or Maternity & Newborn Safety Investigations (MNSI). Furthermore, they will always be considered alongside the Trust's safety reporting and Patient Safety Incident Response Framework (PSIRF) processes.

From 2018, reporting and reviewing eligible perinatal deaths has been part of the Clinical Negligence Scheme for Trusts Maternity Incentive Scheme (MIS). The MIS requires NHS Trusts to evidence that they have met defined core safety actions to improve the quality of care for women, birthing people, babies, and families. If its criteria are not met in any one domain, the Trust will face significant financial implications.

However, aside from the MIS requirements, UHL has an established history of robust and thoughtful review of perinatal deaths and an organisational awareness of the impact of the death of a baby on families. The sensitive care of bereaved families and the striving to improve safety and the prevention of avoidable deaths underpins this standard operating procedure and should always remain the focus.

There is a recognised risk relating to reporting of deaths that occur outside of maternity and the neonatal care setting. Stillbirths and neonatal deaths reported to MBRRACE-UK are 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 can generate reports and verify eligible cases.

2. Perinatal Death Reporting & Review Criteria

2.1 Deaths that require reporting to MBRRACE-UK via the online data collection system www.mbrrace.ox.ac.uk:

- **Late fetal losses** – the baby is delivered between 22 weeks+0 days and 23 weeks+6 days of gestation (or from 400g where an accurate estimate of gestation is not available) showing no signs of life, irrespective of when the death occurred
- **Stillbirths** – the baby is delivered from 24 weeks+0 days gestation (or from 400g where an accurate estimate of gestation is not available) showing no signs of life, irrespective of when the death occurred
- **Early neonatal deaths** – death of a live born baby (born at 20 weeks+0 days gestation of pregnancy or later or 400g where an accurate estimate of gestation is not available) occurring before 7 completed days after birth
- **Late neonatal deaths** – death of a live born baby (born at 20 weeks+0 days gestation of pregnancy or later or 400g where an accurate estimate of gestation is not available) occurring between 7 and 28 completed days after birth

Terminations of pregnancy – Any registered stillbirth or neonatal death resulting from a termination of pregnancy should be notified.

Note: Births showing no signs of life (stillbirths and late fetal losses) – All births delivered from 22 weeks+0 days gestation showing no signs of life must be reported to MBRRACE-UK, irrespective of when the death occurred. This is to ensure complete data collection in line with the WHO guidelines and to allow international comparisons. Please ensure that both the date of delivery and the date of confirmation of death are reported

Note: Post-neonatal deaths – We are no longer collecting information for post-neonatal deaths because of the difficulty in ensuring complete data collection from the wide variety of places of death for these cases.

Note: PMRT reviews – These criteria are not the same as the babies the Perinatal Mortality Review Tool supports review of. Details can be found in the latest version of the document "Guidance for using the PMRT" found in the PMRT section of the website, or the surveillance "User guide" found in the Perinatal surveillance section of the website.

2.2 Deaths that require review using the PMRT tool:

- All late fetal losses 22+0 to 23+6
- All antepartum and intrapartum stillbirths
- All neonatal deaths from birth at 22+0 to 28 days after birth
- All **post-neonatal deaths** where the baby is born alive from **22+0 but dies after 28 following care in a neonatal unit**; the baby may be receiving planned palliative care elsewhere (including at home) when they die.

The PMRT is not designed to support the review of the following perinatal deaths:

- Termination of pregnancy at any gestation.
- Babies who die in the community 28 days after birth or later who have not received neonatal care.
- Babies with brain injury who survive.

2.3 Deaths that require referral to the Child Death Overview Panel (CDOP)

All babies that are born with signs of life and die after birth, regardless of gestation at birth. This excludes babies born following a lawful termination of pregnancy.

2.4 Deaths/births that require referral to Maternity and Newborn Safety Investigations (MNSI)

All term babies born following labour (**at least 37 completed weeks of gestation**), who have one of the following outcomes:

- Intrapartum stillbirth (When a baby was thought to be alive at the start of labour, but was born with no signs of life)
- Early neonatal death (When the baby died within the first week of life (0-6 days) of any cause)
- Potential severe brain injury. (When a baby is diagnosed with a potential severe brain injury (Hypoxic-Ischemic Encephalopathy; HIE/Cooling) thought to have occurred in the first 7 days of life. Definition:
- Was therapeutically cooled (active cooling only), or

- Has been diagnosed with moderate to severe encephalopathy, consisting of altered state of consciousness (lethargy, stupor or coma) and at least one of the following:
    1. hypotonia.
    2. abnormal reflexes including oculomotor or pupillary abnormalities.
    3. absent or weak suck.
    4. clinical seizures.

MNSI do not investigate cases where health issues or congenital conditions (something that is present before or at birth) have led to the outcome for the baby.
The definition of labour used includes:

- Any labour diagnosed by a health professional, including the latent phase (start) of labour at less than 4cm cervical dilatation.
- When the mother called the maternity unit to report any concerns of being in labour, for example (but not limited to) abdominal pains, contractions, or suspected ruptured membranes (waters breaking).
- Induction of labour (when labour is started artificially).
- When the baby was thought to be alive following suspected or confirmed pre-labour rupture of membranes.

All neonatal deaths regardless of gestation need to be discussed with the Medical Examiner prior to completion of the Medical Cause of Death Certificate.

The Medical Examiner decides which deaths need referring to the Coroner with the available clinical information supplied by the Doctor discussing the death.

3. Process for notifying all eligible perinatal deaths & PMRT review

Perinatal death occurs within UHL/LLR

All eligible perinatal deaths should be notified to MBRRACE-UK within 7 working days

MBRRACE-UK Data Collection Form (Appendix 1) completed by the clinical staff and sent via internal post of email to the PMRM, Jarvis Building, LRI.

A minimum of twice weekly screening by PSMRM/PSMRM Admin Support of:

- E3 maternity system
- Badgernet neonatal system
- Daily UHL mortality email notifications
- Weekly ED mortality notifications

Weekly checking by the W&C Patient Safety Manager

PSMRM*/PSMRM Admin** report all eligible deaths on the online MBRRACE-UK database within 7 working days

Prompts:

- CDOP eligible?
- MNSI reportable?

Complete surveillance data of all notified cases within 1 month of the death.

*PSMRM = Band 7 Perinatal Safety and Mortality Review Midwife
**PSMRM Admin = Band 4 Clinical Risk & Quality Facilitator assigned to PMRT

Deaths eligible for PMRT review

- Start review within 2 months of death

To start a PMRT review the factual questions “FQs” need completing within the 2 month timeframe.

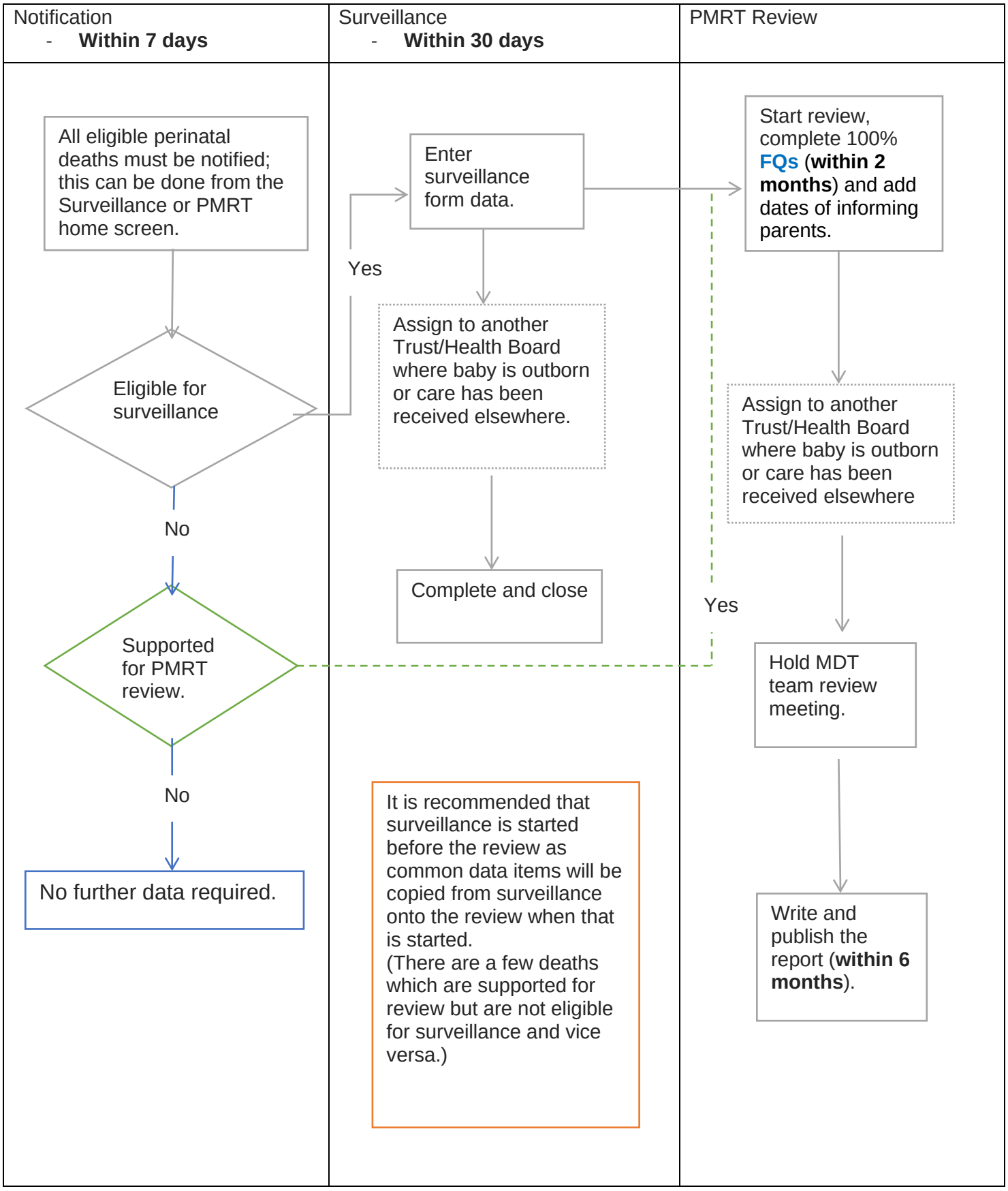
- Review assigned to lead reviewer/s ahead of MDT review meeting.
- Invite expert professionals to meeting
- Initial case review by lead reviewer/s ahead of MDT meeting.
- Discuss case MDT PMRT meeting **within 4 months of the death** (see Appendix 3 for PMRT Terms of Reference
- Complete review following MDT discussion and publish report within a week of the MDT meeting.
- Share final published report with lead Consultants and CDOP if NND

All PMRT review reports should be published within 6 months of the death

Seeking parents’ views of care for PMRT

- Inform parents of the PMRT review process and give written information of the process immediately and 2 weeks of death, (appendix 2).
- Add dates of informing parents to the PMRT review tool within 1 month of the death.
- Weekly check of perinatal review mailbox for parental feedback.
- Contact telephone call to bereaved parents 4-8 weeks following death.
- Feedback added to the PMRT tool.
- Share final PMRT report with lead Consultant/s and feedback to parents via their chosen method.

4. Process for MBRRACE/PMRT



5. Process for notifying all eligible perinatal deaths & PMRT review in full

Process for notifying all eligible perinatal deaths

- All eligible perinatal deaths should be notified to MBRRACE-UK **within 7 working days**.
- Completion of the MBRRACE-UK Data Collection Form (Appendix 1) should be completed by the clinical ward staff.
- For ward areas that have very few eligible perinatal deaths (e.g., ED/CPICU/PICU/Rainbow's Hospice), there are notification systems in place, but this is safety-netted through the process below:
- In case of non-receipt of data collection form - A minimum of twice weekly screening conducted by the Perinatal Safety and Mortality Review Midwife (PSMRM) and PSMRM Admin Support:
    - E3 maternity system
    - Badgernet neonatal system
    - Daily UHL mortality email notifications
    - Weekly ED mortality notifications

- This process to be safety-netted via **weekly** checking by the W&C Patient Safety Manager
- All eligible deaths to be reported on the online MBRRACE-UK database **within 7 working days** by the Perinatal Safety and Mortality Review Midwife (PSMRM) and PSMRM Admin Support.
- In the unlikely event of both the PSMRM and PSMRM being absent for a period >7 working days, responsibility for reporting deaths will be allocated to an alternative member of the quality and safety team by the Quality & Safety. Deaths can be reported by any UHL MBRRACE-UK reporter – list of names on the Teams SharePoint.
- Prompts:
    - Should this death be reported to CDOP? If so - It is the responsibility of the person reporting the eligible death to check that a neonatal death has also been reported to CDOP through the appropriate reporting system for the local CDOP relating to the baby's parental address.
    - Is this death MNSI reportable? If so, ensure that MNSI process followed (see MNSI process).
- Complete surveillance data of all notified cases **within 1 month of the death**.

Process for PMRT Review

- All eligible deaths to have a review started **within 2 months of the death** by PSMRM/PSMRM Admin Support. (In their absence, this can be done by any UHL MBRRACE-UK PMRT reporter – list of names on shared drive).

- To start a PMRT review **100%** of the factual questions **"FQs"** need completing within the 2-month timeframe.
- PSMRM to consider suitability of lead reviewer (obstetric & neonatal where appropriate) for each case and assign accordingly ahead of the MDT review meeting.
- The lead reviewer will consider the need for additional MDT professionals to be invited to the review meeting (e.g., cardiologist/anaesthetist/lead sonographer/palliative care nurse, etc.) where specialist care or pertinent care issues or expertise are recognised outside of maternity/neonates. The lead reviewer will also liaise with PSMRM and PSMRM Admin Support for their invitation to the relevant review meeting.
- The lead reviewer will complete the timeline within the narrative of the PMRT tool and as many of the dropdown questions as possible ahead of the wider MDT discussion (any questions that require clinical judgment/discussion will be brought to the review meeting).
- Case to be discussed at MDT PMRT meeting within four months of the death (see Appendix 3 for PMRT Terms of Reference) – meetings are held twice a month and consist of one meeting (third Thursday of the month) for obstetric only cases and one meeting (first Wednesday of the month) for joint obstetric and neonatal cases. Where timelines are not being met due to several cases, extraordinary meetings are to be arranged by the PSMRM with oversight from the Perinatal Mortality Lead Consultants.
- Review to be completed immediately following MDT discussion and report published by lead reviewer within a week of the MDT meeting. For cases with outstanding clinical details or reports expected (e.g., post-mortem/coronial investigation/MNSI reports, etc.), the PMRT report is to be published with agreed terminology to denote that it is not the final report. Once any outstanding information (e.g., postmortem findings) is available, PSMRM/PSMRM Admin Support requests the report to be reopened by MBBRACE-UK and notify case review lead/s so they can add information and re-publish the report.
- Final published report to be shared with lead Consultants for baby and birthing person, and any feedback to parents ensured.
- Report to be shared with CDOP if relevant via the process related to the local CDOP (i.e. via PMRT tool for LLR CDOP and directly with CDOP leads for deaths where parental address outside LLR)
- All PMRT review reports should be published within 6 months of the death.

MNSI reporting process

- Appropriate registrant, (e.g., PSMRM, Patient Safety Coordinator, Bereavement Midwife, Neonatologist, Obstetrician, Band 7 DS coordinator), discusses MNSI review with parents of baby and gives written information + performs Duty of Candour (alongside PMRT information if appropriate).
- Details of case to be notified to MNSI *notify as "anonymous" until consent for contact details to be shared*.
- Time given for parents to consider MNSI review – contact parents to gain consent for MNSI contact at an appropriate time (liaise with Bereavement Midwives).
- Inform MNSI of outcome of parental consent for contact.
- Requests for information for MNSI are then managed by the PSMRM & PSMRM Admin.

Seeking parents' views of care for PMRT

- As soon as sensitively possible following the death of a baby eligible for PMRT review, appropriate registrant, usually a Bereavement Midwife or PSMRM inform parents of the PMRT review process and written information given (Appendix 2).
- Bereavement Midwives discuss PMRT on a second occasion within 2 weeks of the death as part of their bereavement support to families.
- Bereavement team report dates of informing parents on a weekly basis to PSMRM/ PSMRM Admin.
- Dates of informing parents added to the PMRT review tool within 1 month of the death by PSMRM/ PSMRM Admin.
- Weekly check of perinatal review mailbox by PSMRM/ PSMRM Admin for parental feedback.
- Contact telephone call/letter to bereaved parents by PSMRM 4-8 weeks following death to offer additional opportunity for parental input and ascertain how parents would want outcome of review to be fed back (e.g., at Consultant debrief, written report, face-to-face with clinician/PSMRM/bereavement midwife).
- Any feedback gained via Bereavement Midwives or PSMRM to be added to the PMRT promptly to ensure consideration by the review lead ahead of the relevant meeting.
- Following PMRT review finalisation and publication, report to be shared with lead Consultant/s and feedback to parents via their chosen method.

Learning from PMRT Reviews

Completing the PMRT supports learning and care improvements for future mothers, babies, and families. The review group will translate learning from reviews into actions which will be implemented and monitored to ensure completion. The impact of actions will be audited as appropriate.

A quarterly report will be presented to the Trust's Patient Safety Committee, by the Perinatal Mortality Lead Consultant, to support organisational learning and service improvements. Findings from local reviews, where appropriate, will be fed up regionally and nationally to allow benchmarking and thereby ensure national learning.

6. Monitoring Compliance

What will be measured to monitor compliance	How will compliance be monitored	Monitoring Lead	Frequency	Reporting arrangements
MBRRACE live CNST compliance data[1]	Exporting of the data spread sheet and mapping against in-house perinatal deaths spread sheet. When CNST database is not live stillbirths and neonatal deaths reported to MBRRACE-UK are compared to registered deaths (ONS for England and Wales, NRS for Scotland) in order to identify unreported deaths.	PMRT Midwife	Weekly	Report compliance to Quality & Safety Manager
Monthly MBRRACE-UK/PMRT compliance	Reporting of monthly position by PMRT Midwife	Quality & Safety Manager	Monthly	Maternity Governance Meeting
Quarterly MBRRACE-UK/PMRT compliance	Quarterly Board Report to include details of MBRRACE-UK/PMRT KPI compliance	Perinatal Mortality Lead	Quarterly	Quarterly Board

7. Education & Training

Healthcare Professional	Training required
Perinatal Mortality Safety and Review Midwife Perinatal Mortality Leads	PMRT training delivered by MBRRACE-UK
PMRT Admin Members of the MDT review team Bereavement Midwives	Cascade PMRT training Online PMRT training
Midwives Neonatal Nurses Neonatologists Obstetricians	Inclusion of MBBRACE-UK reporting and PMRT on annual mandatory training sessions
Emergency Department	Dissemination of SOP

[1] In periods when the CNST live data is not available, contingency should be made for weekly download of MBRRACE data to check compliance.

8. Supporting References

UHL Policy for Learning from the Deaths of Patients who have been in our care B4/2023

MBRRACE-UK surveillance user guide v1-7.:
https://www.mbrrace.ox.ac.uk/Content/local/docs/MBRRACE-UK%20surveillance%20user%20guide%20v1-7.pdf?v=638584625100000000

Guidance for using the PMRT for perinatal review:
https://www.npeu.ox.ac.uk/assets/downloads/pmrt/3b_Guidance%20for%20using%20the%20PMRT%20July%202018%20v6.pdf

9. Key Words/Abbreviations

Child Death Overview Panel (CDOP)
Clinical Negligence Scheme for Trusts (CNST)
Coroner- a public official, appointed or elected, in a particular geographic jurisdiction, whose official duty is to make inquiries into deaths in certain categories.
Mothers and Babies: Reducing Risk through Audit and Confidential Enquiries (MBRRACE)
Maternity and Newborn Safety Investigations (MNSI)
Neonatal Death- Death of a live born infant, regardless of gestational age at birth, within the first 28 completed days of life.
Perinatal Mortality Review Tool (PMRT)
Patient Safety Incident Response Framework (PSIRF)
Stillbirth-A baby born dead after 24 completed weeks of pregnancy
Post Mortem-examination of a body after death.

The Trust recognises the diversity of the local community it serves. Our aim therefore is to provide a safe environment free from discrimination and treat all individuals fairly with dignity and appropriately according to their needs.
As part of its development, this policy and its impact on equality have been reviewed and no detriment was identified.

CONTACT AND REVIEW DETAILS			
Perinatal Mortality Lead Consultant - SOP Lead Jo Dickens – Perinatal Safety and Review (PMRT) Midwife Nicola Deakins – Deputy Head of Quality Assurance/Midwife Bhavna Mapara – Senior Project Manager			**Executive Lead** Chief Medical Officer
Details of Changes made during review:			
Date	Issue Number	Reviewed By	Description Of Changes (If Any)
September 2024	1		New SOP

Appendix 1: MBRRACE data collection form

V6.2 Apr 2024

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

Perinatal death data collection form

This form is for internal use only, within the unit of care
Please DO NOT send to MBRRACE-UK

When ready, all data must be submitted to MBRRACE-UK using the electronic data collection system (www.mbrrace.ox.ac.uk)

TYPE OF DEATH

Data should be submitted for the following types of death using information available in the maternal and/or baby case notes and discharge summary:

- ***Late fetal loss*** : a baby delivered between 22^{+0} and 23^{+6} weeks gestational age showing no signs of life, irrespective of when the death occurred.
- ***Stillbirth***: a baby delivered at or after 24^{+0} weeks gestational age (or with a birthweight of 400g or more where an accurate estimate of gestation is not available) showing no signs of life, irrespective of when the death occurred.
- ***Early neonatal death***: A live born baby (born at 20^{+0} weeks gestational age or later, or with a birthweight of 400g or more where an accurate estimate of gestation is not available) who died *before* 7 completed days after birth.
- ***Late neonatal death***: A live born baby (born at 20^{+0} weeks gestational age or later, or with a birthweight of 400g or more where an accurate estimate of gestation is not available) who died *from* 7 completed days after birth but *before* 28 completed days after birth.

IMPORTANT:

Births showing no signs of life (stillbirths and late fetal losses) – all births delivered from 22^{+0} showing no signs of life must be reported to MBRRACE-UK, irrespective of when the death occurred. This is to ensure complete data collection in line with the WHO guidelines and to allow international comparisons. Please ensure that both the date of delivery and the date of confirmation of death are reported.

Termination of pregnancy: Any late fetal loss, stillbirth or neonatal death resulting from a termination of pregnancy should be reported. Limited information is collected in the initial notification only. Items marked * are required in order to complete the notification.

Multiple pregnancies: For multiple pregnancies, please complete additional copies of pages 6 to 8 for each additional birth. Where the death of a baby is confirmed before 20^{+0} weeks gestation but the baby is delivered at 22^{+0} weeks gestation or later AND the birthweight is less than 200g, you will only be required to complete the initial notification for this baby.

Person completing notification

Date of notification

/ /

HQIP · University of Leicester · University of Birmingham · The Newcastle upon Tyne Hospitals NHS · TIMMS · Sands · NHS Chelsea and Westminster Hospital · Oxford Population Health · NPEU

1.1 Woman's identifiers

Family name/surname*

Given name/first name*

Address*

Postcode*

Date of birth* (dd/mm/yyyy) / / or **Age*** (years)

NHS/CHI number*

☐ Tick if ineligible for NHS/CHI number

Hospital number*

1.2 Woman's details

Ethnic category*

- ☐ White British
- ☐ White Irish
- ☐ White other
- ☐ Mixed White and Black Caribbean
- ☐ Mixed White and Black African
- ☐ Mixed White and Asian
- ☐ Mixed other
- ☐ Indian
- ☐ Pakistani
- ☐ Bangladeshi
- ☐ Asian other
- ☐ Black Caribbean
- ☐ Black African
- ☐ Black other
- ☐ Chinese
- ☐ Other
- ☐ Not known

Country of birth

Time resident in UK at booking

☐ < 1 year ☐ ≥ 1 year ☐ Not known

Documented communication difficulties?

☐ Yes ☐ No ☐ Not known

If yes, type of communication difficulties:

☐ Learning difficulties ☐ Language barrier ☐ Other*

Age at leaving full-time education (years)

Woman's qualification attainment level (Select highest or closest)

- ☐ No qualifications
- ☐ 1 - 4 O Levels/GCSE's (any grade)/Entry Level/Foundation Diploma
- ☐ NVQ Level 1/Foundation GNVQ/Basic Skills
- ☐ 5+ O Levels (passes)/CSE (grade 1)/GCSE (grades A* - C)/School Certificate/1 A Level/2 - 3 AS Levels/VCE/Higher Diploma
- ☐ NVQ Level 2/Intermediate GNVQ/City and Guilds Craft/BTEC First or General Diploma/RSA Diploma
- ☐ 2+ A Levels or VCE's/4+ AS Levels/Higher School Certificate/Progression or Advanced Diploma
- ☐ NVQ Level 3/Advanced GNVQ/City and Guilds Advanced Craft/ONC/OND/BTEC National/RSA Advanced Diploma
- ☐ Degree (for example BA, BSc), Higher Degree (for example MA, PhD, PGCE)
- ☐ NVQ Level 4 - 5/HNC/HND/RSA Higher Diploma/BTEC Higher Level
- ☐ Professional Qualifications (e.g. teaching, nursing, accountancy)
- ☐ Other vocational or work-related qualifications
- ☐ Foreign qualifications
- ☐ Not known

Main support during pregnancy

- ☐ Partner (cohabiting)
- ☐ Partner (not cohabiting)
- ☐ Family/friend
- ☐ None
- ☐ Not known

1.2 Woman's details continued

Employment status at booking

- ☐ Employed or self-employed *(full or part-time)*
- ☐ Unemployed *(looking for work)*
- ☐ Retired
- ☐ Student *(full or part-time)*
- ☐ Looking after home/family
- ☐ Permanently sick/disabled
- ☐ Other
- ☐ Not known

Did woman have a partner?

☐ Yes ☐ No ☐ Not known

Partner's employment status at booking

- ☐ Employed or self-employed *(full or part-time)*
- ☐ Unemployed *(looking for work)*
- ☐ Retired
- ☐ Student *(full or part-time)*
- ☐ Looking after home/family
- ☐ Permanently sick/disabled
- ☐ Other
- ☐ Not known

Parents' blood relationship

☐ Unrelated ☐ Other relation
☐ First cousins or closer ☐ Not known

Was woman refugee or asylum seeker?

☐ Yes ☐ No ☐ Not known

Evidence of homelessness or living in temporary accommodation at any point during this pregnancy?

☐ Yes ☐ No

If Yes, accommodation types during this pregnancy (tick all that apply):

- ☐ Emergency accommodation to prevent or relieve homelessness – Bed and breakfast or hotel
- ☐ Hostel or night shelter to prevent or relieve homelessness
- ☐ House/flat where Local Authority has placed family under homelessness duty (Council owned, private landlord, housing association)
- ☐ Supported accommodation to relieve homelessness
- ☐ Rough sleeping/squatting
- ☐ Unspecified temporary accommodation

History of homelessness or living in temporary accommodation at any point prior to this pregnancy?

☐ Yes ☐ No

If Yes, accommodation types prior to this pregnancy (tick all that apply):

- ☐ Emergency accommodation to prevent or relieve homelessness – Bed and breakfast or hotel
- ☐ Hostel or night shelter to prevent or relieve homelessness
- ☐ House/flat where Local Authority has placed family under homelessness duty (Council owned, private landlord, housing association)
- ☐ Supported accommodation to relieve homelessness
- ☐ Rough sleeping/squatting
- ☐ Unspecified temporary accommodation

2.1 Woman's health

Did this woman have any of the following pre-existing medical problems?

☐ Yes *(specify below)* ☐ No ☐ Not known

- ☐ Asthma requiring an increase in treatment or admission to hospital
- ☐ Autoimmune disease e.g. lupus, scleroderma
- ☐ Blood/clotting disorders
- ☐ Cancer
- ☐ Cardiac disease including dysrhythmia
- ☐ Cystic fibrosis
- ☐ Diabetes
- ☐ Endocrine problem other than thyroid disease or diabetes
- ☐ Epilepsy treated with anti-convulsants
- ☐ Genetic/hereditary condition
- ☐ Haematological disorders/haemoglobinopathies
- ☐ Hepatitis B or C
- ☐ HIV
- ☐ Hypertension
- ☐ Inflammatory bowel disease
- ☐ Learning disability
- ☐ Liver disease
- ☐ Physical disability
- ☐ Psychological or mental health problems including eating disorders
- ☐ Renal disease
- ☐ Thrombosis
- ☐ Thyroid disease
- ☐ Transplant
- ☐ Uterine or other significant surgery
- ☐ Other: _____

Tobacco smoking status

- ☐ Never used
- ☐ Non-user at booking (history unknown)
- ☐ Gave up before pregnancy
- ☐ Gave up during pregnancy
- ☐ Smoker
- ☐ Not known

Electronic cigarette use

- ☐ Never used
- ☐ Non-user at booking (history unknown)
- ☐ Gave up before pregnancy
- ☐ Gave up during pregnancy
- ☐ Electronic cigarette user
- ☐ Not known

2.1 Woman's health continued

Breath carbon monoxide (parts per million)

☐☐

Was there documented alcohol abuse?

☐ Yes ☐ No ☐ Not known

Was there documented substance abuse?

☐ Yes ☐ No ☐ Not known

3.1 Previous pregnancies

Number of previous pregnancies (Please copy this sheet if more than 4 previous pregnancy outcomes)

☐☐ For each previous pregnancy, please list all fetuses and babies and their outcomes.
For stillbirths and live births, please also state birth weight; for live births, please also indicate whether an infant death occurred.

Pregnancy number	Fetus number	Outcome (all births)	Year (all births)	Gestation (weeks) (all births)	Birth weight (grams) (SB & LB only)	Infant death? (LB only
☐☐	☐ of ☐	☐ TOP ☐ Fetal loss *(0-23 w)* ☐ Stillbirth *(≥24 w)* ☐ Live birth	☐☐☐☐	☐☐	☐☐☐☐	☐ Yes ☐ No ☐ Not known
☐☐	☐ of ☐	☐ TOP ☐ Fetal loss *(0-23 w)* ☐ Stillbirth *(≥24 w)* ☐ Live birth	☐☐☐☐	☐☐	☐☐☐☐	☐ Yes ☐ No ☐ Not known
☐☐	☐ of ☐	☐ TOP ☐ Fetal loss *(0-23 w)* ☐ Stillbirth *(≥24 w)* ☐ Live birth	☐☐☐☐	☐☐	☐☐☐☐	☐ Yes ☐ No ☐ Not known
☐☐	☐ of ☐	☐ TOP ☐ Fetal loss *(0-23 w)* ☐ Stillbirth *(≥24 w)* ☐ Live birth	☐☐☐☐	☐☐	☐☐☐☐	☐ Yes ☐ No ☐ Not known

3.2 Obstetric history

Did this woman have any of the following previous pregnancy complications?

☐ Yes *(specify below)* ☐ No ☐ Not known

☐ Abruption
☐ Baby with a birthweight >4.5kg
☐ Caesarean section in any past pregnancy
☐ Excessive gestational weight gain
☐ Gestational diabetes
☐ Group B Strep infection in a previous baby
☐ Growth restricted baby/small for gestational age baby
☐ Placenta accreta/increta/percreta
☐ Pregnancy induced hypertension
☐ Pregnancy related mental health problems
☐ Pre-term birth <34 wks gestation
☐ Rhesus or other incompatibility disease
☐ Severe pre-eclampsia/HELLP/eclampsia
☐ Shoulder dystocia
☐ Three or more miscarriages (<24/40)
☐ Thromboembolic disease
☐ Uterine abnormality e.g. bicornuate uterus
☐ Uterine surgery or related surgery (other than CS) including surgery for uterine rupture
☐ Other: ______________________________

4.1 Booking

Intended place of birth at booking*

Type of unit

☐ Obstetric unit
☐ Alongside midwifery unit
☐ Freestanding midwifery unit
☐ Home
☐ Freebirthing
☐ Other
☐ Undecided
☐ Never booked
☐ Not known

Type of care

☐ Obstetrician led
☐ Midwifery led
☐ Freebirthing
☐ Shared (obstetric & midwifery co-care)
☐ Not known

Name of unit/hospital intended to provide care

[ ]

4.1 Booking continued

Date of first booking appointment (dd/mm/yyyy)

☐☐ / ☐☐ / ☐☐☐☐

Final estimated date of delivery (EDD) (dd/mm/yyyy)

☐☐ / ☐☐ / ☐☐☐☐

Basis of final EDD

- ☐ Dating ultrasound scan
- ☐ Last menstrual period
- ☐ Not known

Number of babies present at the dating scan

☐

Chorionicity

- ☐ Dichorionic, diamniotic
- ☐ Monochorionic, diamniotic
- ☐ Monochorionic, monoamniotic
- ☐ Trichorionic, triamniotic
- ☐ Other triplet or higher order multiples chorionicity
- ☐ Not known

Assisted conception

- ☐ Not assisted
- ☐ Ovulation induction only *(e.g. clomiphene)*
- ☐ In-vitro fertilisation (IVF) including egg donation
- ☐ Intra-cytoplasmic sperm injection (ICSI)
- ☐ Artificial insemination with/without ovulation induction
- ☐ Not known

Height (cm)

☐☐☐

First recorded weight (kg)

☐☐☐

First recorded BMI (if either height or weight unavailable)

☐☐ . ☐

4.2 Antenatal care provision

Documented poor appointment attender (two or more missed appointments)?

☐ Yes ☐ No ☐ Not known

Was there a transfer of care between booking and onset of labour?

☐ Yes ☐ No

Reason if there was transfer of care

- ☐ Higher level of maternal care required
- ☐ Higher level of neonatal care required
- ☐ Higher level of maternal & neonatal care required
- ☐ Organisational
- ☐ Other
- ☐ Return to home unit
- ☐ Not known

Intended place of birth at onset of care in labour*

Name of unit/hospital providing care at onset of labour

Type of unit

- ☐ Obstetric unit
- ☐ Alongside midwifery unit
- ☐ Freestanding midwifery unit
- ☐ Home
- ☐ Freebirthing
- ☐ Other
- ☐ Undecided
- ☐ Not known

Type of care

- ☐ Obstetrician led
- ☐ Midwifery led
- ☐ Freebirthing
- ☐ Shared (obstetric & midwifery co-care)
- ☐ Not known

Was there a transfer of care between onset of labour and birth?

☐ Yes ☐ No

Reason if there was transfer of care

- ☐ Higher level of maternal care required
- ☐ Higher level of neonatal care required
- ☐ Higher level of maternal & neonatal care required
- ☐ Organisational
- ☐ Other
- ☐ Return to home unit
- ☐ Not known

Actual place of birth*

Name of unit/hospital providing care at birth

4.2 Antenatal care provision continued

Type of unit

- ☐ Obstetric unit
- ☐ Alongside midwifery unit
- ☐ Freestanding midwifery unit
- ☐ In transit
- ☐ Home
- ☐ Other

Type of care

- ☐ Obstetrician led
- ☐ Midwifery led
- ☐ Freebirthing
- ☐ Unattended
- ☐ Shared (obstetric & midwifery co-care)
- ☐ Other
- ☐ Not known

5.1 Delivery and outcomes summary

Note: If reporting more than one death from this pregnancy, please complete an additional copy of pages 6 to 8 for each additional birth.

Case definition*

- ☐ Late fetal loss *(a baby delivered between 22^{+0} and 23^{+6} weeks gestational age† showing no signs of life, irrespective of when the death occurred)*
- ☐ Stillbirth *(a baby delivered at or after 24^{+0} weeks gestational age† showing no signs of life, irrespective of when the death occurred)*
- ☐ Fetal loss before 22 weeks *(as part of a multiple pregnancy)*
- ☐ Early neonatal death *(a live born baby [born at 20^{+0} gestational age or later†] who died before 7 completed days after birth)*
- ☐ Late neonatal death *(a live born baby [born at $^{20+0}$ weeks gestational age or later†] who died from 7 completed days after birth but before 28 completed days after birth)*
- ☐ Currently alive

† Or from 400g where an accurate estimate of gestation is not available

Termination of pregnancy*

- ☐ Yes
- ☐ No

Reason for termination of pregnancy*

- ☐ Congenital anomaly
- ☐ Fetal reduction
- ☐ Not known
- ☐ Maternal health
- ☐ Other

5.1A Labour and delivery

Onset of labour

- ☐ Spontaneous
- ☐ Induced
- ☐ Never in labour
- ☐ Not known

Presentation at delivery

- ☐ Vertex
- ☐ Breech
- ☐ Brow/Face
- ☐ Other
- ☐ Not known

Date and time of onset of care in labour, or start of induction *(dd/mm/yyyy hh:mm)*

☐☐ / ☐☐ / ☐☐☐☐ ☐☐ : ☐☐

Attempted modes of delivery *(tick all that apply)*

- ☐ Spontaneous vaginal
- ☐ Ventouse
- ☐ Non-rotational forceps
- ☐ Rotational forceps
- ☐ Assisted breech
- ☐ Breech extraction
- ☐ Destructive operative delivery
- ☐ Pre-labour caesarean section
- ☐ Caesarean section after onset of labour
- ☐ Perimortem caesarean section

Final mode of delivery

- ☐ Spontaneous vaginal
- ☐ Ventouse
- ☐ Non-rotational forceps
- ☐ Rotational forceps
- ☐ Assisted breech
- ☐ Breech extraction
- ☐ Destructive operative delivery
- ☐ Pre-labour caesarean section
- ☐ Caesarean section after onset of labour
- ☐ Perimortem caesarean section
- ☐ Not known

Type of caesarean section (if applicable)

- ☐ Immediate threat to life of mother or fetus
- ☐ Maternal compromise that is not immediately life threatening
- ☐ No maternal or fetal compromise but needs early delivery
- ☐ Delivery timed to suit woman or staff (elective)
- ☐ Not known

Primary indication for caesarean section

- ☐ Abnormal presentation
- ☐ Previous caesarean section
- ☐ Fetal compromise
- ☐ Maternal compromise
- ☐ Slow progress
- ☐ Other
- ☐ Not known

Was the baby born in water?

- ☐ Yes
- ☐ No
- ☐ Not known

Delivery complications (tick all that apply)

- ☐ None
- ☐ Shoulder dystocia
- ☐ Cord prolapse
- ☐ Cord accident
- ☐ Antepartum haemorrhage
- ☐ Other
- ☐ Not known

5.1A Labour and delivery continued

Date and time of delivery/birth* (dd/mm/yyyy hh:mm)

☐☐ / ☐☐ / ☐☐☐☐ ☐☐ : ☐☐

5.1B Baby/fetus outcomes (all deaths)

Baby's given name/first name*

Sex of fetus or baby*

☐ Male ☐ Indeterminate
☐ Female ☐ Not known

NHS/CHI number* (if stillbirth or livebirth)

☐☐☐ ☐☐☐ ☐☐☐☐ ☐ Tick if ineligible for NHS/CHI number

Hospital number*

Ethnic category*

☐ White British
☐ White Irish
☐ White other
☐ Mixed White and Black Caribbean
☐ Mixed White and Black African
☐ Mixed White and Asian
☐ Mixed other
☐ Indian
☐ Pakistani
☐ Bangladeshi
☐ Asian other
☐ Black Caribbean
☐ Black African
☐ Black other
☐ Chinese
☐ Other
☐ Not known

Birth order / Number of babies at delivery

☐ of ☐

Birth weight* *(grams)*

☐☐☐☐

Gestation at delivery* *(weeks + days)*

☐☐ + ☐

Signs of life in first minute (include any signs, even if stillbirth or late fetal loss)

Heart beat

☐ Yes *(select rate band from below)*
- ☐ < 100 bpm (< 60 bpm)
- ☐ ≥100 bpm
- ☐ < 100 bpm (60 – 99 bpm)
- ☐ Not known
- ☐ < 100 bpm (unspecified)

☐ No ☐ Not known

Cord pulse

☐ Yes *(select rate band from below)*
- ☐ < 100 bpm (< 60 bpm)
- ☐ ≥100 bpm
- ☐ < 100 bpm (60 – 99 bpm)
- ☐ Not known
- ☐ < 100 bpm (unspecified)

☐ No ☐ Not known

Active body movement

☐ Yes ☐ No ☐ Not known

Respiratory activity

☐ Yes ☐ No ☐ Not known

Apgar score

At 1 minute ☐☐ At 5 minutes ☐☐

Resuscitation at birth

Was active respiratory support provided?

☐ Yes (select active respiratory support outcome):
- ☐ Condition stabilised and neonatal care provided
- ☐ Attempts to sustain life were stopped

Number of minutes after which attempts were stopped ☐☐

☐ Not known

☐ No (state reason active respiratory support not provided):
- ☐ Condition stable, resuscitation not required
- ☐ Decision made prior to birth
- ☐ Decision made following review of care at delivery

Other issues

Documented child protection issues

☐ Yes ☐ No ☐ Not known

Documented history of domestic violence

☐ Yes ☐ No ☐ Not known

5.1B Baby/fetus outcomes (late fetal losses & stillbirths only)

Gestation at confirmation of death (weeks + days)

☐☐ + ☐

Date death confirmed*

☐☐ / ☐☐ / ☐☐☐☐

5.1B Baby/fetus outcomes (late fetal losses & stillbirths only) continued

Baby alive at onset of care process that led to delivery

☐ Yes ☐ No ☐ Not known

5.1B Baby/fetus outcomes (live births only)

Was baby admitted to a neonatal unit?

☐ Yes ☐ No

Place of death*

Type of unit

☐ Labour ward ☐ PICU ☐ In transit
☐ Neonatal unit ☐ A&E ☐ Other
☐ Paediatric unit ☐ Home ☐ Not known

Name of unit/hospital/hospice providing care at time of death

If the baby did not die in hospital what was the reason for the transfer?*

☐ Baby transferred here for palliative care ☐ Baby was discharged home ☐ Baby was never in hospital

Unit of care prior to transfer for palliative care/discharge

Was the death unattended?

☐ Yes ☐ No

Date and time of death* (dd/mm/yyyy hh:mm)

☐☐ / ☐☐ / ☐☐☐☐ ☐☐ : ☐☐

5.1C Cause of death

Sources of information used to determine cause of death (tick all that apply)

☐ Hospital post mortem
☐ Coroner's/procurator fiscal's post mortem
☐ Limited post mortem examination
☐ Placental histology
☐ Clinical assessment

Baby/fetus primary cause of death (as written in notes or on the Death Certificate)

Further details of primary cause of death (if appropriate)

Baby/fetus associated condition (maximum 2)

1.

2.

Is this the final agreed cause of death following results of any inquest and all requested investigations (e.g. post-mortem, placental histology, blood and genetic tests, perinatal mortality review?

☐ Yes ☐ No – awaiting results

5.1D Post-mortem

Was a post-mortem offered?

☐ Yes ☐ No ☐ Not known

Was consent given for a post-mortem?

☐ Full ☐ None
☐ Limited ☐ Not known

Consented procedures (tick all that apply)

☐ MRI
☐ X-ray
☐ Other (please specify)

Was a post-mortem undertaken?

☐ Full ☐ None
☐ Limited ☐ Not known

Undertaken procedures (tick all that apply)

☐ MRI
☐ X-ray
☐ Other (please specify)

5.1D Post-mortem continued	
Was placenta sent for histology? ☐ Yes ☐ No ☐ Not known	**Was the case discussed with a coroner/procurator fiscal?** ☐ Yes ☐ No ☐ Not known **Was the case accepted as a coroner/procurator fiscal's case?** ☐ Yes ☐ No ☐ Not known
Comments	

Once this form is complete, all data must be transferred to the MBRRACE-UK online data entry system: www.mbrrace.ox.ac.uk

Appendix 2: Parent letters

University Hospitals of Leicester NHS Trust

Women's & Children's Services CMG
Leicester
LE1 5WW
Tel: 0300 303 1573
Switchboard Fax: 0116 258 7565
Minicom: 0116 287 9852

Date: _____

Dear Parent/s

Understanding what happened – hospital review (PMRT)

We are so sorry that your baby has died.

We appreciate that this is a difficult time to be reading new information. However, it is important to understand as much as we can about what happened and why your baby died.

In order to do this in the coming months a team of different healthcare professionals such as midwives, obstetricians (maternity doctors) and neonatologist (baby doctors) at University Hospitals of Leicester NHS Trust will hold a meeting and review the care you and your baby received.

The review will:

- look at medical records, tests and results, including a post mortem if you have consented to one
- answer any questions you may have and address any concerns
- talk to staff involved
- look at guidance and policies to ensure the care you received was appropriate

The review may tell us that we need to change the way we do things or that good and appropriate care was given to your family.

Involving you

Your views are important; it would be helpful for you to share your feelings and thoughts about your care or ask any questions you have with us. To support you in doing this we have provided you with a key contact:

Key Contact Name & Telephone Number:

Your Key Contact will:

- call you to inform you again about the review process
- ask if you would like to ask any questions or give your views to the review team
- give you choices about how you might do this

Letting the review team know your questions or feedback:

There are a variety of ways you can share your questions or feedback with the team:

- ✓ Verbally over the telephone or face-to-face with your key contact
- ✓ Verbally with the midwife that coordinates the review process, **Jo Dickens**. Her contact details are 07950 884 155
- ✓ You can email your questions or feedback to our dedicated email address at perinatalreview@uhl-tr.nhs.uk
- ✓ Write to us at PMRT Review Team, Quality & Safety Office, Jarvis Building, Leicester Royal Infirmary, LE1 5WW

We will ensure an interpreter is provided if you need one.

Keeping you informed

It may take 6 months to gather all the information required for a review meeting. We understand that this is a long time to wait and if you would like to meet with a Consultant before the review takes place, you can arrange this through your key contact. We may, however, not have any further information about what happened and why your baby died by then.

Receiving feedback from the review

Your key contact will ask you if and how you would like any information from the review shared with you, whether you have asked the team any questions or not. We aim to have the outcome of the review available before you meet with the Consultant/s who looked after you and your baby in the hospital (usually 12-14 weeks after birth). This is so they can discuss it with you at that meeting. However, this is not always possible due to the time it takes to gather all the information for review. If this happens, you can either ask to postpone your Consultant meeting until the review outcome is ready or we can organise a separate meeting at a later date. You may choose to discuss the review with Jo Dickens or your key contact instead.

Thank you for reading this information at such a sad and difficult time

Please contact your Key Contact or Jo Dickens to discuss any of the information further or if you need any assistance in understanding the review process. We are here to support you as best we can.

Kind regards

Jo Dickens
Perinatal Safety and Review Midwife
07950 884 155

Appendix 3: UNIVERSITY HOSPITALS OF LEICESTER NHS TRUST
WOMEN'S AND CHILDREN'S CMG
Perinatal Mortality Review Panel Meeting
Terms of Reference

Membership

- Three Obstetric Consultants
- Two Neonatal Consultants including one who is the representative on CDOP
- Senior Neonatal Nurse (Matron)
- Senior Midwife (Matron)
- Community Midwife representative
- Professional Midwifery Advocate
- Bereavement Midwife(s)
- Clinical Risk & Quality Representative(s)
- Child Death Overview Panel Manager or Deputy
- ICB Representative(s) – (as an external overview)
- PMR Panel Admin support
- Patient Safety Champion
- Consultant Midwife
- MNVP Lead

The Perinatal Mortality Lead Consultant will attend one meeting per month; will attend at least 4 of each meeting during the year (obstetric only and joint).
The chair of each meeting will normally be the Perinatal Safety & Mortality Review Midwife (PSMRM). In their absence the meeting may be chaired by any Consultant. The Chair will be indicated by entering the role against their name on the PMRT tool at the beginning of each case discussion.
Other specialities will be invited for individual cases as required (e.g. anaesthetics, genetics, safeguarding and surgery).

Ex Officio

- Obstetric Head of Service
- Neonatal Head of Service
- Clinical Director
- Head of Midwifery
- Observers may attend in order to facilitate professional development by arrangement with Chair.

Quorum for Obstetric Meeting

- One Obstetric Consultant
- One Midwife
- One Clinical Risk & Quality Representative

Quorum for Obstetric/Neonatal Meeting

- One Obstetric Consultant
- One Neonatal Consultant

- One Matron (Obstetrics or Neonatology)
- One Clinical Risk & Quality Representative

Purpose of our PMRT stillbirth and neonatal mortality review meetings:

- To provide a robust, comprehensive, and multi-disciplinary investigation into all eligible stillbirths, neonatal deaths and infant deaths on the neonatal unit;
- To provide an analysis of quality of care and preventability;
- To develop action plans that aim to address the contributory factors identified and achieve organisational change and service improvements;
- To identify trends/themes for further investigation;
- To identify and disseminate lessons and recommendations arising from the reviews;
- To recognise a "just culture" of accountability for individuals and organisations;
- To incorporate the parents' perspective of their care and address any questions and concerns they have;
- Provide quarterly reports to CMG Board, Maternity and neonatal Governance and Risk meetings;
- To provide parents with a robust explanation of why their baby died (accepting that, despite full clinical investigations, it is not always possible to determine this for every baby);
- Provide a report for the Leicester, Leicestershire & Rutland Child Death Overview Panel.

The conduct of our PMRT meetings includes:

- Making every effort to gather the relevant information/evidence about each death in advance of the meeting;
- Attending and arriving on time to the meeting;
- Participating actively in discussions;
- Respecting everyone's ideas and way of expressing them;
- Accepting robust discussion and disagreement;
- Agreeing to be comprehensive, open and transparent throughout;
- Trying as much as possible (recognising this can be challenging) to accept that your own actions can be questioned;
- Respecting the confidentiality of the documents and discussions that take place during the meetings and record/dispose of them appropriately;
- If gaps are identified in the information there may be a need to go away and gather more information before completing the review;
- Using the national Perinatal Mortality Review Tool (PMRT) to support the conduct of each review.

Process:

- Cases for review to be brought to the meeting for the next month. Panel members to be allocated cases thought appropriate according to their background.

- Panel members to complete the case on PMRT or the review pro forma seeking further specialist advice where necessary. The completed review pro forma to be presented at the following meeting.
- Decisions on the quality of care given to be agreed by a majority of the panel. The chair to have the deciding vote.
- Notes to be made at each meeting of cases discussed, decisions regarding quality of care and lessons learnt. Action log to be maintained.
- The notes to be distributed to all members of the panel and ex officio members and forwarded to the Directorate Board. They will also be available on the Perinatal Mortality shared drive.

Frequency:

The Neonatal/Obstetric meetings will be held every month 09:30 to 12:30, on the 1st Wednesday of the month.

The Obstetric meetings will be held every month 09:30 to 12:30, on the 3rd Thursday of the month.

More frequent or ad-hoc meetings may be required as a result of business pending.