

National Perinatal Mortality Review Tool

Learning from Standardised Reviews When Babies Die

National Perinatal Mortality Review Tool

Sixth Annual Report



December 2024





















Sheffield Children's

UNIVERSITY^{OF} BIRMINGHAM

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Glossary

Child Death Overview Panel (England)
A cot which is kept cool/ cold to preserve the baby's body after death
Cardiotocograph
National Child Mortality Database
The collaboration established to deliver the MNI-CORP
Maternal, Newborn and Infant Clinical Outcome Review Programme
Perinatal Mortality Review Tool
Stillbirth and neonatal death charity

Use of the terms women and mothers

We use the terms 'women' and 'mothers' throughout this report 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 important that evidence-based care for maternity, perinatal and postnatal health is inclusive.

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Learning from Standardised Reviews When Babies Die – 2024 Annual Report

Key Messages – December 2024

Since the launch of the national Perinatal Mortality Review Tool (PMRT) in early 2018, over 27,000 reviews have been completed. This report presents the findings for reviews completed from January to December 2023. Here are the key messages from the 4,311 reviews completed during this period.

Supporting high quality local perinatal reviews



Learning from Standardised Reviews When Babies Die – 2024 Annual Report



30%

of reviews identified at least one issue with care that may have made a difference to the outcome for the baby 95%

of reviews identified areas for improvement in care



Lay Summary

The reasons for PMRT reviews are to provide answers for families, to see whether different care might have changed the outcome for the baby and to improve care to help prevent future baby deaths. The reviews in this report were completed in 2023 when UK health services were struggling with staff shortages and strikes. Despite these challenges, there were improvements in how the PMRT was used to review care when a baby died.

Supporting families through the PMRT review process is essential to help them meaningfully engage in the process and manage their grief. Meaningful involvement in the review of the care the family received supports maternity services to improve future care. Parents need a clear explanation of the review and clear guidance about how they can provide feedback or ask questions if they wish. Recently, documents to help services support parent engagement were updated and are now available online. Training is also available for PMRT users to help support them with parent engagement in reviews.

After each review is complete, the overall care for that family is given a grade where A is 'no issues with care', B is 'issue with care found which would not have impacted the outcome', and C or D are 'issue with care found which may, or would likely have, affected the outcome' respectively. This grade helps the staff to decide whether any changes in care are needed. Over time, the UK gradings of care has changed so that they are lower (fewer As and Bs and more Cs and Ds). The number of baby deaths in our annual report has gone down over the years, and just over half of reviews now include a healthcare worker who works outside of the unit where care was provided as an external reviewer. These changes all suggest that healthcare workers are able to be more critical of the care they provide, that improvements are found more often and that the quality of action plans has improved.

Conducting a thorough review means examining all stages of care. To do this well, it is important to include a range of healthcare workers. There has been an improvement in the number of different healthcare professionals involved in review teams, however, improvements still need to be made. The involvement of administrative and risk and governance support team members present at reviews is still low, meaning support for, and development of, action plans could be better. Only two thirds of reviews had a member of the bereavement team present, meaning there may not be someone at every review meeting to specifically ask questions on behalf of the parents. There needs to be enough resources for staff to make sure that reviews are high quality and completed in good time.

The issues with care found in this report are similar to those in previous reports, for example, a poor location and quality of bereavement rooms continues to affect 1 in 10 parents. These issues should remain a focus for quality improvement. The findings reported here also show that improvements across all areas of care are needed to reduce the number of baby deaths across the UK. PMRT findings should be used to identify and fund actions to make improvements to care for mothers, babies and families in future.

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Executive Summary

The reviews reported in this, the sixth national PMRT annual report, were carried out in 2023, the year the World Health Organisation declared the end of the COVID-19 global health emergency. Nevertheless, UK clinical services continued to be challenged with staff shortages and industrial action by NHS staff. Despite this, there were continued improvements in the use of the PMRT to carry out reviews of care when babies die.

The review of care when a baby has died is part of routine maternity and neonatal care and is not an optional extra. The purpose of review is to provide answers for bereaved parents and families about their care, and explore whether different care may have resulted in a different outcome. Wider learning also comes from review findings to implement care quality improvements to prevent future adverse safety events and baby deaths.

Supporting parents and families through bereavement and the review process is essential. Meaningful engagement with parents and families in the process has the potential to improve the quality of reviews from which parents will benefit directly as well as contributing to wider learning. In order to engage with the review, parents need a straightforward verbal explanation, in a language they can understand, of the purpose and process of review and their role. Verbal explanations need to be supported by 'plain language' parent-facing written information. Materials developed and recently updated by the PMRT collaboration to support parent engagement are available for use by trusts and health boards. Training for PMRT users, including how to support parent engagement, is also available.

There has been a general shift in the holistic grading of care suggesting that the discipline of robust self-critical examination is being embraced more widely, with the need for improvements in care identified more frequently. The quality of the action plans developed following the identification of issues with care has also shown an improvement. These plans indicate a greater focus on 'strong' and 'intermediate', system level changes with actions designed to reduce the capacity for human error rather than 'weaker' actions aimed at the behaviour of individuals. With the general decrease in perinatal mortality rates and more reviews having an external panel member, these changes seem likely to represent an increasingly self-critical approach to review, rather than necessarily representing poorer care; a positive development if this is the case.

Conducting a thorough, robust and system¬atic review of all stages of the pregnancy and neona¬tal care journey is a multidisciplinary activity. There has been a steady improvement in the number of healthcare profession-als involved in review teams over time with a reduction in reviews conducted by three or fewer staff members. Despite the challenges in making these arrangements, just over half of reviews also now involve a clinician external to the trust/health board who is present to provide independent 'fresh eyes' and robust challenge. Ideally, all reviews would benefit from the presence of an external clinician, but without additional resources this is unlikely to be achieved easily. Of concern, administrative support for reviews, which reduces the administrative burden for clinical staff, continues at a low and less than ideal level. Implementation of identified actions requires the presence of members of the risk management and governance team and there has only been a marginal increase in their presence since the last report. Similarly, with a member of the bereavement team present for only two thirds of reviews their role in advocacy for the parents cannot be fulfilled for everyone.

The issues with care identified in this report are largely focused around the same areas as in previous reports, including screening for fetal growth restriction, management of reduced fetal movements and diagnosis and management of maternal medical, surgical and social issues; assess¬ment of maternal risk status and staffing issues during labour and birth; thermal and respiratory manage¬ment once the baby has been born; and the qual¬ity of neonatal documentation. The inadequate location and quality of bereavement suites continues to affect 1 in 10 parents. These issues should therefore remain a focus of quality improvement activities.

Evidence of the impact of reviews leading to quality improvement (QI) activities comes from a survey of PMRT users we conducted in 2024. An example of impact includes the substantially decreasing proportion over time of reviews identifying maternal screening of the need for antenatal aspirin as an issue. The introduction of 'strong' system level actions to address this issue was mentioned by multiple survey respondents.

Fully realising the benefits of local reviews and consequent service improvements requires adequate resourcing to ensure that high quality and timely reviews are carried out. Resourcing involves including review activities in job plans for consultants, both in-house and also so they can also act as externals, and prioritising the time of other staff. The alternative is to continue to fund expensive external enquiries and investigations after the fact.

The national findings reported here underline that multiple, incremental and sustained improve¬ments across all aspects of care are required to make a substantial difference to the perinatal mortality rate of individual trusts and health boards, and nationally. Evidence from robustly conducted PMRT reviews should form the basis for individual organisations to identify and fund the necessary actions to improve future care. Examples from the survey reported here of QI activities for particular issues with care provide examples of how trusts and health boards have improved their care which could be adopted by other organisations.

Recommendations

 Evaluate the approach to parent engagement in reviews, ensure staff are trained and use the available PMRT Parent Engagement materials, particularly in trusts and health boards where fewer parents are engaged with the review process.

Action: Trusts and health boards, staff caring for bereaved parents, service commissioners

2. Provide adequate resourcing of PMRT review teams, including administrative support, and risk and governance team members.

Action: Trusts and health boards, service commissioners

- Provide adequate resourcing to ensure the involvement of independent external clinicians in review teams.
 Action: Service commissioners
- 4. Use the local PMRT summary reports and this national report as the basis to prioritise resources for key aspects of care and quality improvement activities identified as requiring action.

Action: Trusts and Health Boards, Service Commissioners, regional/network support systems, Govern ments

5. Improve service quality improvement activities implemented as a consequence of reviews by developing 'strong' actions targeted at system level changes and audit their implementation and impact. Review and implement relevant examples of 'strong' quality improvement activities in this report to improve service delivery.

Action: PMRT review teams, governance teams in Trusts and Health Boards, Service Commissioner

Background

The fundamental aim of the PMRT is to support objective, robust and standardised local reviews of all stages of care when babies die. This is to provide answers for bereaved parents and their families about whether the care that they and their baby received was appropriate, safe and personalised and whether different care may have changed the outcome. The second, but nonetheless important, aim is to ensure local and national learning results from review findings to improve care, reduce safety-related adverse events, prevent future baby deaths and improve care for all mothers, babies and families. This report provides the national level data for reviews carried out in 2023.

The PMRT is designed to support the review of baby deaths, from 22 weeks' gestation onwards, including late miscarriages, stillbirths, and neonatal deaths. For the majority of parents, the PMRT review process is likely to be the only hospital review of their baby's death that will take place.

This sixth annual report builds on previous reports and presents an analysis of reviews completed from January 2023 to December 2023. In contrast to previous reports, we have now moved to reporting by calendar year so it is important to note that some reviews presented here (Jan and Feb 2023) will also have been included in the previous report. There is a vast amount of information presented here and we have provided a separate Tables document, which includes data from this year and all previous reports for comparison. You can download this to refer to wherever we have referred to Table data in the text. Brief versions (data for the last three reports) of certain tables are also included in this main report document. The technical report and an infographic of the main findings are also available separately.

The main focus of this year's report is yet again 'quality' in terms of parent engagement, the review process, action-plans and subsequent quality improvement implementation.

Findings

1. Reviews completed

Since it was launched in 2018, all trusts and health boards across England, Wales, Scotland and Northern Ireland have adopted the PMRT and by the 17th October 2024 over 27,000 reviews had been started and/or completed using the tool.

During 2023, a review of care was started for 98% of all babies who died in the perinatal period comprising 98% of stillborn babies and those who died in the late second trimester (late miscarriages), and 96% of babies who died in the neonatal period (first four weeks after birth) (Figure 1). Whilst overall only 88% of deaths were reviewed to completion and the report printed, the proportion of deaths where a review has been started and completed has increased since the launch of the tool, and notably so for neonatal deaths (Figure 2). See Tables 1.1 to 1.4 in the data tables report.

In the rest of this report the findings presented relate to the 4,311 reviews completed in the period January 2023 to December 2023 inclusive and the final review report printed; findings from reviews started but not completed are not included. See Table 1.5 below and in the data tables report. The findings reported here come from the information entered into the PMRT when each review is carried out.

	Reviews Mar 2021 to Feb 2022		Reviews Mar 2022 to Feb 2023		Reviews Jan 2023 to Jan 2024	
	Number of reviews N = 4,199	Percentage of reviews	Number of reviews N = 4,111	Percentage of reviews	Number of reviews N = 4,311	Percentage of reviews
Country:						
England	3,746	89%	3,583	87%	3,806	88%
Wales	171	4%	186	5%	154	4%
Scotland	235	6%	190	5%	176	4%
Northern Ireland*	47	1%	152	4%	175	4%
Type of death:						
Late miscarriages	416	10%	383	9%	395	9%
Stillbirths	2,394	57%	2,248	55%	2,327	54%
Neonatal deaths	1,389	33%	1,480	36%	1,589	37%

Table 1.5: Characteristics of the reviews by country and type of death (note table numbers correspond with the tables report)



Figure 1: Proportion of deaths where a review was started by country and type of death, 2023



Figure 2: Proportion of deaths where a review was started by year and type of death, 2018 to 2023

2. Parent engagement

Engaging parents in PMRT reviews means:

- 1. Ensuring parents are made aware that a review of their care and that of their baby will take place in an appropriate mode and language, understanding that it is important to remove medical jargon, to be sensitive and sympathetic and to use a language appropriate to the parent/s including an interpreter where necessary.
- 2. Ensuring that parents are given the opportunity to voice any questions, comments or feedback about what happened to them and their baby and about any aspect of their care; using plain, considerate language and a preferred method of communication (and being aware parents may not wish to, or may take longer to engage). Feedback from parents provides a fuller picture of the care received and can be instrumental in learning and for providing better care in future.
- 3. Ensuring that parents are given the outcome of the PMRT review by offering to meet to discuss the review findings, followed by sending a clear, accessible letter explaining the review findings and what was discussed in the meeting, and the PMRT report if they request it (we would never advise that the report is sent out to families without a verbal and written explanation of what it means).

In their immediate grief, and often shock, parents may not feel able to express any questions or concerns and will need to be given time and often more than one opportunity to do so. People process grief and traumatic events differently and at their own pace. Some parents may <u>never</u> wish to engage with the review process. However, by being transparent and receptive, healthcare workers can provide the space for parents to come back with questions and any feedback which may be valuable not only to their mental health and processing their grief, but to the review of their care. See Engaging Parents below and Appendix A for information about the materials developed by the PMRT team to support parent engagement.

Were parents told that a review would take place?

From the information entered into the PMRT, 97% of UK parents were reported as having been informed that a review of their care would take place. This varied from 98% in England, 98% in Scotland, 86% in Wales and 89% in Northern Ireland (Figure 3), representing a small overall increase from the previous report.





Were parents' perspective of their care sought?

Of the parents who were told that a review would take place, their perspectives of the care they received was reported as having been sought from 96%. This ranged from 98% in England, 91% in Scotland, 86% in Wales to 79% in Northern Ireland.

Did parents feel able to express their views?

For just over half of reviews (55%), there was at least one comment, question or concern expressed by parents recorded. These included some positive comments about their care generally or particular staff members.

From the information recorded in the PMRT it was unclear what proportion of parents had been approached where they specifically indicated they had no comments or questions about their care. Nor was it possible to fully distinguish this group from the group of parents who had been approached but no questions, concerns or comments had been received back from the parents by the time of the review, or where the comment was, for example, 'no concerns'. To improve future reporting the relevant questions in the PMRT have been extended and clarified. Comments in the PMRT should only be noted where they have come from parents.

Parental comments, feedback and concerns expressed

A total of 2,367 reviews (55%) included comments, questions or concerns from parents; of those who provided any feedback, 56% provided multiple comments. A random sample of 200 of these were analysed (Figures 4 & 5) and illustrative parental quotes are given in Figure 6. A quarter of the parents' comments (25%) were positive feedback about their care. This represents an increase from 17% in the previous report, (see Table 2.2 in the data tables report).



Figure 4: Comments, questions and concerns about care expressed by parents where a late miscarriage or stillbirth occurred, Jan 2023 to Dec 2023



Figure 5: Comments, questions and concerns about care expressed by parents where a neonatal death occurred, Jan 2023 to Dec 2023

The majority of questions from parents were specific to what had happened and why their baby had died (33%) together with concerns about the management plans and the care they had received (22%). Lack of compassion from staff (3%) alongside loss of control in terms of not being listened to and feeling they were being ignored (2%) accounted for 5% of comments. Notably, expressions of feelings that they were not being listened to or that there was a lack of compassion were reported less frequently than in the previous report; 5% versus 10%.

Some parents asked very general questions about their care and had issues with communication, questioning why they were not given particular information which would have been relevant to their care (16%).

A range of other comments and questions (2% in total) related to procedural and administrative issues. Of note, in the previous report, 3% of comments and questions were expressions of maternal/paternal self-blame and guilt, for example, asking if the baby's death was caused by something they either did or didn't do and 2% of comments were reflections of grief; in the current report, no comments in the sample of 200 reviews analysed fell into these categories. Whilst representing population-based data, it should be noted that the information about parents' questions and concerns comes via the trusts and health boards and not directly from parents.



Figure 6: What parents said about their care. Reviews completed Jan 2023 to Dec 2023

3. The review team

It is essential that the teams of professionals undertaking PMRT supported reviews reflect the multidisciplinary teams who provide maternity and neonatal care, and that these teams are appropriate for the care being reviewed. Single individuals, or even two or three members of staff, are unlikely to be able to appropriately and objectively assess all aspects of the care provided; conducting a high quality review is a multidisciplinary activity. Ideally, all reviews should involve an external panel member who is there as a 'fresh eyes' and to provide independent challenge to ensure the review is as objective as possible. Guidance about the inclusion of an external panel member is given in Appendix B.

There has been a steady improvement over time in the composition of the review teams which are now more multidisciplinary than in previous years. This is reflected in the median number of staff present for reviews which has increased from five in 2018-19 to nine in 2023, see Table 3.1.

In 2023, 11% of reviews were conducted by three or fewer individuals, similar to 2022-23 (10%), compared with 15% in 2021-22 and 35% in 2018-2019. Two thirds (63%) of all reviews were carried out by a team consisting of eight or more professionals, representing an increase from just over half (58%) in 2022-2023. This represents an increase in reviews for both neonatal deaths (71% compared to 68% in 2022-23) and late miscarriages and stillbirths (58% compared to 53% in 2022-23), see Table 3.2.

Improvements in the multidisciplinary nature of review teams is further illustrated by more PMRT reviews having a member of the bereavement team present. This has increased from 59% of reviews in 202-23 to 64% in 2023-24 (Figure 7). See Appendix B for details about the roles in PMRTs.



Figure 7: Proportion of reviews with specific professionals present for the review, Jan 2023 to Dec 2023

Having a neonatologist or paediatrician present for reviews of neonatal deaths has remained stable at 84%, having increased from 59% in 2021-2022. There has been no further improvement in the proportion of reviews of neonatal deaths where a neonatologist/paediatrician is present.

Having a member of the PMRT review team who is external to the trust/health board and able to provide a 'fresh eyes' independent perspective is strongly recommended ¹. The proportion of reviews benefiting from the presence of an external member of the review team has increased from 45% in 2022-23 to 51% in 2023.

¹ Kirkup B. The Report of the Morecambe Bay Investigation. London: The Stationery Office. 2015 The Report of the Morecambe Bay Investigation (publishing. service.gov.uk) (accessed 5th July 2022)

Conducting high quality reviews requires all of the relevant information to be available for the review team at the review meeting. Having administrative support ensures this happens and enables timely reviews to be carried out in the most efficient and effective way. The proportion of reviews undertaken with administrative support remained consistent (36% compared with 35% in the previous report). This means that most reviews appear to lack this support.

The presence of members of the risk and governance team is important to ensure that learning from reviews is translated into actions, which are implemented and subsequently audited. These team members were present for three-quarters of reviews and this has only slightly increased since the last report (78% compared with 74% 2022-23).

4. Issues with care identified

Overall, in 95% of reviews at least one issue with care was identified (19 out of 20) (Table 4.1). In 30% (6 out of 20) of reviews at least one issue with care that was relevant to the outcome for the baby was identified; this is an increase from 20% in the previous year.

4a) Pre-conception and antenatal care

Overall, 6,664 issues with pre-conception and antenatal care were identified of which 1,680 (25%) of the issues were identified by the review panel as relevant to the outcome. The most common issues identified largely reflected the findings from earlier reports. The five most common issues with pre-conception and antenatal care were:

- 1. Late booking or unbooked identified in 30% of reviews
- 2. Inadequate growth surveillance identified in 23% of reviews
- 3. Smoking assessment and management -identified in 23% of reviews
- 4. Delay in diagnosis or inappropriate management of medical, surgical or social problems identified in 22% of reviews
- 5. In adequate investigation or management of reduced fetal movements --identified in 13% of reviews

There frequency with which these issues were identified was similar compared with the previous year (see Table 4.2).



Figure 8: Proportion of reviews with issues during pre-conception and antenatal care, Jan 2023 to Dec 2023

Having increased slightly to 30% compared with 27% in the previous report and 15% in 2018-2019, late booking or not having booked at all was the most commonly identified issue at this stage of care, although the proportion of pregnancy outcomes for which this issue was relevant was unchanged at 10%. From the information available it is not possible to discern why the frequency with which late booking or not having booked has increased as an issue over time.

Of note, screening and management of high risk women requiring antenatal aspirin is no longer in the group of most frequently reported antenatal issues. Having been identified in 23% of reviews in 2018-2019 this has reduced to 5% of reviews in 2023 (see Table 4.2).

4b) Labour and birth

Overall 3,216 issues with labour and birth were identified of which 1,023 (32%) of the issues were identified by the review panel as relevant to the outcome (see Table 4.3).

Reviews Mar 2021 to Feb 2022			Mar 2022 b 2023	Reviews Jan 2023 to Dec 2023		
Issue group	Number and percentage of reviews with each issue N=4,199 n (%)	Number of issues relevant to the outcome N=979 n (%*)	Number and percentage of reviews with each issue N=4,111 n (%)	Number of issues relevant to the outcome N=792 n (%*)	Number and percentage of reviews with each issue N=4311 n (%*)	Number of issues relevant to outcome N=1023 n (%*)
lssues with monitoring of the mother ¹	914 (22%)	92 (9%)	886 (22%)	84 (11%)	936 (22%)	89 (9%)
Fetal monitoring issues ²	311 (7%)	185 (19%)	244 (6%)	121 (15%)	319 (7%)	157 (10%)
No assessment of mother's risk status or inadequate management at the start of her care in labour or during the course of her labour	281 (7%)	108 (11%)	266 (6%)	85 (11%)	311 (7%)	103 (10%)
Staffing issues ³	233 (6%)	121 (12%)	194 (5%)	88 (11%)	296 (7%)	153 (15%)
Issues with communication with mothers with poor/no English	283 (7%)	23 (2%)	260 (6%)	33 (4%)	289 (7%)	28 (3%)

Table 4.3:The five most common issues with care identified during intrapartum care, 2021 to
2023

The five most common issues with care identified during labour and birth reflected the findings from earlier reports with the proportions affected essentially unchanged since 2020-2021. The five most common issues with care during labour and birth were:

- 1. Maternal monitoring in labour identified in 22% of reviews
- 2. Fetal monitoring in labour identified in 7% of reviews
- 3. Inappropriate assessment of maternal risk status at the start of and/or during the course of labour – identified in 7% of reviews
- 4. Staffing issues (including insufficiently senior staff involved in care and lack of one-to-one care in established labour) identified in 7% of reviews
- 5. Communication with mothers who have poor or no English identified in 7% of reviews



Figure 9: Proportion of reviews with issues during labour and birth Jan 2023 to Dec 2023

4c) Newborn care

Overall there were 2,781 issues with care of the newborn baby encompassing the initial resuscitation and stabilisation, transfer to the neonatal unit (including further onward transfer to an external unit) and during ongoing neonatal care. Of these, 552 (20%) were identified as relevant to the outcome (see Table 4.4).

,	Reviews I		Reviews I	Mar 2022	Poviowe	lan 2023
	Reviews Mar 2021 to Feb 2022		to Feb		Reviews Jan 2023 to Dec 2023	
Issue group	Number and percentage of reviews with each issue N=1,389 n (%)	Number of issues relevant to outcome N=453 n (%)	Number and percentage of reviews with each issue N=1,480 n (%)	Number of issues relevant to outcome N=468 n (%)	Number and percentage of reviews with each issue N=1,589 n (%)	Number of issues relevant to outcome N=552 n (%)
Inadequate documentation:						
At all stages of care	1,132 (81%)	73 (16%)	882 (60%)	77 (18%)	1,237 (78%)	75 (14%)
Resuscitation & stablisation	609 (44%)		447 (30%)	51 (12%)	563 (35%)	51 (9%)
Transfer to neonatal unit	91 (7%)		54 (4%)	8(2%)	77 (5%)	5 (1%)
Neonatal care	353 (25%)		297 (20%)	15 (4%)	311 (20%)	16 (3%)
Transfer to an external neonatal	79 (6%)		84 (6%)	<10	96 (6%)	3 (1%)
Thermal management issues:						
At all stages of care	376 (27%)	123 (27%)	367 (25%)	108 (26%)	439 (28%)	140 (25%)
Resuscitation	48 (3%)		26 (2%)	<10	50 (3%)	24 (4%)
Neonatal care	78 (6%)		91 (6%)	33 (8%)	103 (6%)	26 (5%)
Transfer to neonatal unit/other	250 (18%)		250 (17%)	69 (16%)	286 (18%)	90 (16%)
Issues during resuscitation with	:					
Respiratory management ¹	209 (15%)	66 (15%)	174 (12%)	57 (14%)	214 (13%)	62 (11%)
Delayed cord clamping	61 (4%)	6 (1%)	76 (5%)	16 (4%)	98 (6%)	14 (3%)
Resuscitation not in line with NLS	49 (4%)	21 (5%)	29 (2%)	14 (3%)	53 (3%)	21 (4%)
Issues during neonatal care with	1:					
Cardiovascular management ²	60 (4%)	6 (1%)	64 (4%)	16 (4%)	58 (4%)	15 (3%)
Respiratory management	69 (5%)	18 (4%)	86 (6%)	25 (6%)	92 (6%)	25 (5%)
Issues with communication with parents ³	108 (8%)	11 (2%)	85 (6%)	9 (2%)	95 (6%)	10 (2%)

Table 4.4:The most common issues with care identified during neonatal care (excluding end
of life care), for the four time periods from Jan 2018 to Dec 2023

1. **Includes:** issues around establishing ventilation, intubation, positive pressure respiratory support, oxygen saturation monitoring and administration of surfactant

2. Includes: line placement and radiological confirmation of line position

3. Includes: mothers/parents with poor/no English and at any stage of resuscitation, transfer and neonatal care

As with earlier stages of care, these issues with neonatal care also reflect the issues identified in previous reports. Problems with documentation were again highlighted in 78% of reviews at all stages of, with 35% of reviews identifying issues with documentation during resuscitation and stabilisation and 20% during care on the neonatal unit.

There was also a high percentage of reviews (28%) where thermal management was identified an issue, particularly during transfer to the neonatal unit or other locations (18%). Respiratory management was also commonly identified as an issue with care (13% of reviews).

All the findings in relation to neonatal care represent an increase in the proportion of reviews where these issues were identified compared with the previous year; for documentation issues the increase was larger, 78% compared with 60% previously.



Figure 10: Proportion of reviews relevant to the outcome with issues during resuscitation, stabilisation, transfer and neonatal care, Jan 2023 to Dec 2023

4d) Issues with postnatal investigations and bereavement care

The single most common issue with postnatal investigations remains that of the need for the baby to be transferred to another hospital for post-mortem when this investigation is requested (25%) (see Table 4.6). A further issue, once again affecting 6% of reviews, is that the placental histology was not carried out by a perinatal/paediatric pathologist which, as has been identified in the MBRRACE-UK confidential enquiries², is likely to have affected the quality and value of this examination.

In terms of bereavement care, the absence of a policy, support and practical help to enable parents to take their baby home was identified in 18% of all reviews. Further, inadequate documentation regarding taking the baby home was found in 10% of reviews (see Table 4.7). Whilst only a small proportion of parents may wish to take their baby home, they have the right to make an informed choice about this important aspect of their care after the death of their baby, and will need help and support to decide what to do.

² Draper ES, Gallimore ID, Kurinczuk JJ, Kenyon S (Eds.) on behalf of MBRRACE-UK. MBRRACE-UK 2019 Perinatal Confidential Enquiry: Stillbirths and neonatal deaths in twin pregnancies. The Infant Mortality and Morbidity Studies, Department of Health Sciences, University of Leicester: Leicester, 2021. www.npeu.ox.ac.uk/assets/downloads/mbrrace-uk/reports/perinatal-report-2020-twins/MBRRACE-UK_Twin_ Pregnancies_Confidential_Enquiry.pdf (accessed 26th October 2023).

Table 4.7: The most common issues with bereavement care* identified from Aug 2020 to Dec 2023

	Reviews Mar 2022 to Feb 2023			Reviews Jan 2023 to Dec 2023			
Issue group	Number of reviews of late miscarriages and stillbirths N=2,631 n (%)	Number of reviews of neonatal deaths N=1,180 n (%)	Number of all reviews N=4,111 n (%)	Number of reviews of late miscarriages and stillbirths N=2722 n (%)	Number of reviews of neonatal deaths N=1589 n (%)	Number of all reviews N=4311 n (%)	
Policy, support and practical help to take their baby home was not available	459 (17%)	289 (24%)	748 (18%)	484 (18%)	297 (19%)	781 (18%)	
Inadequate documentation regarding taking the baby home	312 (12%)	201 (17%)	513 (12%)	245 (9%)	176 (11%)	421 (10%)	
Inadequate documentation regarding access to a cold cot	77 (3%)	144 (12%)	221 (5%)	53 (2%)	111 (7%)	164 (4%)	
Inadequate documentation regarding transfer to mortuary care	111 (4%)	100 (8%)	211 (5%)	77 (3%)	90 (6%)	167 (4%)	
Location and quality of the bereavement suite inadequate including being affected by service modifications due to the pandemic ¹	243 (9%)	104 (9%)	347 (8%)	273 (10%)	116 (7%)	389 (9%)	
Inadequate documentation to tell if bereavement care respected cultural, religious and spiritual wishes of the parents	124 (5%)	107 (9%)	231 (6%)	113 (4%)	94 (6%)	207 (5%)	

¹Bereavement care questions were incorporated into the PMRT in August 2020

²Specific pandemic related questions were incorporated into the PMRT in August 2020

³Includes six additional issues each affecting 50 or fewer reviews overall

An inadequate location and quality of the bereavement suite, including being affected by pandemic modifications, was identified in 9% of reviews.

The quality of bereavement care was difficult to assess in many instances due to inadequate documentation available to the PMRT review team. The areas where documentation was inadequate included taking the baby home, whether wishes were respected, transfer to mortuary care, assessment for a cold cot, whether or not bereavement care included practical help or emotional support, and assessment of the location and quality of the bereavement care (see Table 4.7 for more detail).

The National Bereavement Care Pathway (NBCP) identifies nine standards for good bereavement care (Figure 11). These provide the basis for establishing high quality bereavement care services and can then be used to audit the service. More information is available on the NBCP website

https://nbcpathway.org.uk/



Figure 11: National Bereavement Care Pathway – standards for good bereavement care

5. Grading of care

Towards the end of each review, the review team is required to provide an overall grading of care for each stage of the care pathway, including bereavement care. This provides a holistic grading summary indicative of the extent to which improvements in care, had they been implemented, may have affected the outcome (Figure 12). See Tables 5.1 to 5.6. The 'outcome' here refers to the death of the baby but also the psychosocial outcomes for parents.



Figure 12: Grading of care by stage of care, Jan 2023 to Dec 2023



Figure 13: Grading by stage of care with the presence of an external member of the review team, Mar 2022 to Feb 2023

Over time, there had been a steady decrease in the proportion of reviews of pregnancy and labour care for late miscarriages and stillbirths where the care has been graded as A (no issues with care identified). This is now stable with 42% at this grade in 2023 compared with 41% in the 2022-2023 report, 50% in 2021-22 annual report and 62% in the first annual report. This change is largely accounted for by a commensurate increase in reviews with care graded as B (issues with care that would have made no difference to the outcome for the baby).

There has been an increase in the proportion of the reviews graded as A for the whole pathway of care for babies who died in the neonatal period with 38% now being grade A, compared with 32% in the previous report. There has been a slight decrease in the proportion with care graded as B (38% vs 47% in the previous year) and there has been a decrease in the proportion graded C&D (issues with care that may or were likely to have made a difference to the outcome) from 18% in 2022-23 to 9%. The grading of bereavement care for all babies has remained stable where the care is graded A (66%).

There has been a steady increase over time in the proportion of reviews where a member external to the trust/health board is present (now 51% of all reviews, where last year it was 45%). This has been associated with a small but persistent change in the distribution of the grading of care with a slightly greater proportion of reviews graded as C&D and fewer A or B when an external reviewer is present (Figure 13) compared with reviews overall.

6. Action plans

At the end of each review, where any issues with care have been identified, each issue is examined in turn to enable the review team to agree if:

- 1. The issue was likely to have been relevant or not to the outcome for the mother and baby
- 2. Whether the issue requires action to improve future care, regardless of the relevance for the particular mother and baby.

For example, screening for gestational diabetes may have been indicated but not carried out, however, the baby died from an unrelated cause. Whilst this omission in care was not relevant to the particular baby's death, the reasons for the omission nevertheless needs to be investigated and systems put in place to ensure that all eligible women are screened in future.

A total of 9,922 separate actions were planned over the course of the 4,311 reviews conducted. This represents an average of just over two actions per review; not all reviews resulted in an action plan and some had more than two actions identified.

The strength of actions

In previous reports we highlighted the need to include action plans which are "strong", where the reliance on individuals to carry out the correct action is removed³ for example, implementing a system-level design to no longer require individual action. These use standardisation and permanent physical or digital designs to eliminate human error and are sometimes referred to as 'forcing actions' (see Appendix C for further information). Action strength is illustrated with examples in Figure 14.

³ US Department of Veterans Affairs. Root Cause Analysis Tools. VA National Center for Patient Safety.REV.02.26.2015.(Pgs26-29) RCA Step by Step Guide REV 07.01.2016 (va.gov)

	Issues	Actions
ctions	The medication management for the baby during the first 24 hours of arrival on the neonatal unit was not appropriate	Clear labelling of adrenaline in the drug cupboard. Medication now in red resus bags and emergency trolley is now to be colour coded and RED.
Strong actions	This mother and her partner were not able to be cared for in either a sound proofed room or a room away from other mothers and crying babies because the necessary facilities are not available	Currently no soundproof facilities on NNU. Plans in place to get soundproofing to walls and door. Awaiting estates to compile quotes. Money in place for refurbishment
actions	This mother had a risk factor(s) for having a growth restricted baby but serial scans were not performed at correct times/ intervals	Guidance updated and USS request form amended to prompt earlier USS where required.
Intermediate actions	This mother presented with reduced fetal movements and there is no evidence that during her antenatal care she had been given written information about what to do if she experienced a change in fetal movements	The antenatal notes include information about fetal movements and women are being updated with videos of actions to take if reduced fetal movements.
Weak actions	It is not possible to tell from the notes if the relevant professionals involved in the ongoing care of the parents were informed about the death of their baby	Learning point highlighted on learning point poster.
Weak	The ongoing respiratory management of the baby on the neonatal unit was not appropriate	Medical staff teaching session to be arranged

Figure 14: The strength of actions associated with illustrative issues 2023

A random sample of 100 action plans was coded by strength. Comparing Figures 15 and 16 illustrates that the proportion of strong and intermediate actions combined has increased in this period and now represent 54% of all actions compared with 51% in the previous year.



Using PMRT evidence to improve care

Following the completion of a review for a specific mother and baby, the review is closed and a final report of the review is produced. This should be used for discussion of the review findings with the parents and as the basis for writing the 'plain language' follow-up letter to parents.

The PMRT system can also be used to produce summary reports of the findings of all reviews carried out over a period of time, with the period of time defined by the person generating the summary report from the PMRT system. Many teams in trusts and health boards use this summary report as a basis of quarterly mortality reporting to their Executive Board which, for trusts in England, can form part of the compliance with Safety Action 1 of the national Maternity Incentive Scheme ⁴.

Recurring issues identified as requiring action but for which there is no immediate solution are identified in these reports. This can be used as a means of highlighting any resource implications and writing business cases to improve care and outcomes.

Quality improvements following PMRT reviews

The implementation of care quality improvements which are identified as a consequence of a PMRT review happens once the review is closed. As a consequence where there is information about action plans included in the PMRT system, whether or not the planned actions led to care quality improvements cannot be determined from the PMRT system. To collect this information we conducted a survey of PMRT lead users to gather data regarding service improvements implemented as a consequence of PMRT review findings. Service users from 38 trusts and health boards completed the survey. The majority supplied information about more than one improvement; 116 were outlined in total.

An extended list of these quality improvement (QI) examples is available on the PMRT website at https:// www.npeu.ox.ac.uk/pmrt/quality-improvement-ideas. Figures 16 to 19 provide some examples from the different stages of care. A substantial proportion of these QI activities represent strong actions with system level changes. For example, risk assessment of the need for antenatal aspirin was added to the electronic patient record (EPR) thereby ensuring that the questions were asked of all women, modifications to the EPR ensured that the sepsis screen results were all simultaneously visible so none were missed (Figure 16). Maternity triage areas were physically reorganised to reduce the chances of delays in assessing women (Figure 17); new equipment was purchased to avoid inadvertent extubations of babies on the neonatal unit (Figure 18); and bereavement suites were restructured and sound proofed to provide a more appropriate environment to care for grieving parents (Figure 19).

⁴ NHS Resolution Maternity Incentive Scheme: https://resolution.nhs.uk/services/claims-management/clinical-schemes/clinical-negligencescheme-for-trusts/maternity-incentive-scheme (accessed 26th October 2023)

Issues identified from PMRT reviews	QI implemented as a consequence
Risk assessment of the need for antenatal aspirin (at risk of fetal growth restriction/ pre-eclampsia) was repeatedly missed – mentioned by multiple respondents.	Risk assessment questions added to the Electronic Patient Record (EPR) system – mentioned multiple respondents
High risk women being advised to obtain the aspirin they need from pharmacy – mentioned by multiple respondents	Patient Group Direction (PGD) established to enable midwives to prescribe aspirin – mentioned by multiple respondents
High risk women being advised to obtain the aspirin they need from pharmacy	The hospital pharmacy supplies packs of aspirin so high risk women in antenatal clinic can be given a supply immediately they have been identified as requiring aspirin
There was a delay in identification, escalation and treatment of maternal sepsis following prolonged rupture of membranes	Modifications were made to the EPR so that the sepsis screen results are all simultaneously visible on one screen
Delayed presentation of women with reduced fetal movements (RFM)	RFM guidance was added to the EPR
For women who missed their glucose tolerance test (GTT) appointment or declined there was not a robust process in place to ensure they were fully informed regarding the risks	DNA/decline protocol for GTT screening was developed and implemented
Low detection rate of SGA/GRF – carried out a review of USS images for missed cases of SGA	Developed a scan quality improvement protocol

Figure 17: Antenatal care: examples of quality improvements implemented following PMRT review findings

Issues identified from PMRT reviews	QI implemented as a consequence
A woman attended triage with reduced fetal movements. She had a set of maternal observations but the fetal heart was not auscultated until a bed was available this resulted in a 90 mins delay; the CTG was pathological	Assessment couches have been added to the triage area so all women can be fully assessed on arrival
A woman presented in early labour she was not triaged immediately. When she was finally seen there was no fetal heart.	Developed a new triage process using RAG rating to inform the on-going process of care.
The maternity assessment unit (MAU) was separated into a rapid assessment unit and a day assessment unit	The hospital pharmacy supplies packs of aspirin so high risk women in antenatal clinic can be given a supply immediately they have been identified as requiring aspirin
Women arriving at triage unbooked were not being booked in a timely manner and therefore not having an ultrasound scan within an appropriate timeframe.	A booking process was developed specifically for use in triage
Delay in diagnosis of preterm pre-labour rupture of membranes in triage.	Triage process and BSOTS* guidance were reviewed. As a consequence the triage process was transformed. The triage area was moved separating it from delivery suite with dedicated staff, rooms and phone lines
Mothers with babies with known lethal congenital anomalies who declined TOP were not offered early birth planning	Birth plan templates were modified to include antenatal, intrapartum and neonatal care for mothers/babies with lethal congenital anomalies

*BSOTS - Birmingham Symptom-specific Obstetric Triage System

Figure 18: Labour and birth care: examples of quality improvements implemented following PMRT review findings

Issues identified from PMRT reviews	QI implemented as a consequence
Babies cold on arrival in the neonatal unit – mentioned by multiple respondents	Neonatal warm care bundle implemented – mentioned by multiple respondents
Unable to intubate a small pre-term baby on labour ward – mismatch between the ETT tube and introducer	Purchased appropriate ETTs for labour ward
Poor recognition of pale babies – especially in mixed race babies	Developed new guideline to introduce haemoglobin testing as a standard part of resuscitation
An increase in episodes of unplanned extubations noted	Conducted audit, identified the fixation device as problematic
Introduced new fixation devices, re-audit found a 50% reduced incidence of unplanned extubations	Triage process and BSOTS* guidance were reviewed. As a consequence the triage process was transformed. The triage area was moved separating it from delivery suite with dedicated staff, rooms and phone lines
Poor documentation resulting in many "unable to say if" on PMRT	Resuscitation protocol amended: scribe allocated and debrief immediately after the resuscitation to confirm the management undertaken.

Figure 19: Neonatal resuscitation and neonatal care: examples of quality improvements implemented following PMRT review findings

Issues identified from PMRT reviews	QI implemented as a consequence
Environment in maternity unsuitable for caring for bereaved families – mentioned by multiple respondents	Maternity services area was restructured to enable a quiet bereavement suite to be established – mentioned by multiple respondents
The unit has a bereavement room however this is not soundproofed – mentioned by multiple respondents	Soundproofing of bereavement suite undertaken – mentioned by multiple respondents
Lack of support/counselling for women and families following pregnancy loss/baby loss	Trust employed a psychotherapist to whom all our bereaved families are referred and we work on an opt-out basis. They can attend when they feel ready which can be many months after their bereavement
Lack of support/counselling for women and families following pregnancy loss/baby loss	Full-time bereavement midwife employed
Parents not always offered the opportunity to take their baby home	New bereavement booklets developed supporting staff with paperwork and care plans for bereaved families, which specifically asks maternity staff if they have asked the parents if they wish to take their baby home.

Figure 20: Bereavement care: examples of quality improvements implemented following PMRT review findings

7. PMRT developments

Engaging parents in reviews

The process of engaging parents with reviews is sensitive and relational to operationalise. For information about how the review process is seen directly from a parent perspective, Sands has carried out a survey of their members' experience of the review into their baby's death. Sands also heard from marginalised groups in a focus group research project the 'Listening Project' (Appendix D). Key findings from a trust and health board staff survey of the use of PMRT engagement materials are available on the P MRT web<u>site: www.npeu.ox.ac.uk/pmrt/reports</u>.

Templates for clinical staff to use in their interactions with parents were developed by the PMRT team to support parent engagement in 2019. These were updated in 2024 using the Person-Based Approach⁵ to development, which includes conducting interviews and iteratively updating materials when feedback is received.

A subgroup of PMRT collaborators was established including academics, clinicians, a behavioural psychologists and individuals with lived experience of perinatal death. The group initially reviewed the materials and made some changes using their experience and expertise. Clinicians who use the PMRT (PMRT leads; midwives, n = 5) were interviewed to gather their perspectives about using the current materials including the changes they would make and the different ways in which they might communicate with parents.

Ten interviews with parents were then conducted online, including three bereaved fathers (n = 13). Parent backgrounds varied with White British, Black British, European and Indian heritages being represented. Interviews were conducted using a Think-Aloud approach5 which involves participants reading the materials and letting the interviewer know their immediate reactions, thoughts and feelings during their first read-through. By using this type of interview as opposed to retrospective feedback, it is possible to more easily ascertain any text which may be unclear, needs to be amended, or worded more sensitively.

New templates are now available on the PMRT website at <u>www.npeu.ox.ac.uk/pmrt/parent-engagement-</u> <u>materials</u>:

- A leaflet for pre-discharge information about the PMRT review,
- Post-discharge contact (template for letter or email)
- A feedback form for parents' comments or questions (Word document and an editable PDF)
- A follow-up for use if no contact has been made
- A flowchart outlining the PMRT process for parents, see Appendix E.

To improve information accessibility for parents, all of the documents have been translated into Welsh and the ten most commonly spoken languages other than English in the UK. These are also available to download from the PMRT website.

⁵ Yardley, L., Morrison, L., Bradbury, K., & Muller, I. (2015). The person-based approach to intervention development: application to digital healthrelated behavior change interventions. Journal of medical Internet research, 17(1), e30. https://doi.org/10.2196/jmir.4055.

Training

At the start of 2024, we began to provide live online training courses for staff in units to support all aspects of the use of the PMRT to carry out reviews. Thus far, we have provided four courses, over two afternoon sessions per course to 146 PMRT users. The course includes presentations about enhancing parent engagement, a technical demonstration of the PMRT, using the PMRT to support reviews, running the review panels, working within teams and with external reviewers, creating action plans and using the information from the reviews to facilitate better communication with parents and support parent feedback. These presentations are delivered by experts in each field. We include question and answer sessions to discuss the presentations, issues and advice from the attendees, and to troubleshoot any issues with the attendees use of the tool. We requested feedback from attendees for each of the presentations and the course overall to make iterative improvements and ensure we include pertinent information throughout.

The course proved to be in high demand and feedback about the utility and relevance of the content was overwhelmingly positive. Each course was limited to fifty attendees to facilitate discussion in the Q&A sessions. However, to ensure our training is more accessible and to keep pace with demand, we have started to develop an online, on-demand, course for staff which incorporates the information and support delivered in our live course. Course participants will be able to complete the sessions at their own pace, at a time suitable to them, and will be able to review material at a later date. To ensure that the learning from Q&A sessions is continued, we will have live on-line Q&A sessions as an adjunct to the course. The online on-demand course will be rolled out at the beginning of 2025 and will be free to PMRT users.

Sands provide free training to support staff in delivering meaningful parent engagement (Appendix D).

Reducing the duplication of notifications of perinatal deaths

For some time we have been working on the integration of notifications of neonatal deaths from the MBRRACE-UK/PMRT platform to enable the flow of this information directly to Child Death Overview Panels (CDOPs) and the National Child Mortality Database (NCMD) in England. Originally, we had planned that along with the notification of the death the information from the completed PMRT review would also be forwarded thus meeting the information requirements of both the CDOP and NCMD. However, following the phase 1 roll out to a small number of volunteer trusts and CDOPs we have identified a substantial number of developments, which are needed before the full integration, can proceed for all trusts and CDOPs. In the meantime, we are planning to launch the integration for just the notification of neonatal deaths in January 2025. This will mean that the duplicated activity of notifying all neonatal deaths to MBRRACE-UK and separately notifying the same deaths to the local CDOP will stop. A single notification will be made to MBRRACE-UK, which will then flow to the relevant CDOP and then to the NCMD.

We have also been working on the integration with the Single Notification Portal (SPEN) being developed by NHS England. This will enable a single notification of a perinatal or maternal death to be sent to relevant national organisations including MBRRACE-UK/ PMRT, NHS Resolution Early Notifications, and the Maternity and Newborn Safety Investigation programme (MNSI) formerly known as HSIB and now located at the Care Quality Commission (CQC). The SPEN is planned for launch in 2025.

Conclusions and recommendations

The review of care when a baby has died is part of routine maternity and neonatal care and should not be regarded as an optional extra. It is therefore reassuring to see an increasing proportion of baby deaths have been reviewed using the PMRT each year since its launch in 2018. During 2023, a review of care

using the PMRT was started for 98% of baby deaths. For 88% of deaths the review was completed and the report was printed out, which is an improvement from 83% in 2022. This is despite the significant challenges that maternity and neonatal services continue to face with staff shortages and the industrial action, which was underway in 2023.

Whilst it is reassuring to know that when the vast majority of baby deaths occur, the care is now reviewed using the PMRT, the next important consideration is the quality of the reviews carried out. One essential aspect of this is the quality of parent engagement in the review process. Parent engagement refers to ensuring that parents are aware that a review of their care and that of their baby will take place and that if they have any questions, concerns or comments about their care, they are invited to express them. This is to ensure that any questions they have are addressed in the review process so that at the feedback stage, once the review is complete, the parents' questions can be answered. To be able to do this, parents need to be given help to understand what a review is and what the process means. This requires a straightforward verbal explanation, in a language they can understand, supported by 'plain language' parent-facing written information, and that communication should be open throughout the review process. 'Parent Engagement' materials developed by the PMRT collaboration were recently updated with the involvement of bereaved parents, and are available on the PMRT website⁶.

For 97% of deaths, it was reported that parents were told that a review would take place and 96% of parents were reported as having been invited to provide comments about their care. These figures contrast with the findings from a Sands online survey of parents who were bereaved in 2021-2023 where only 78% of parents who responded indicated that they were aware that a review would be carried out and only 64% were given the opportunity to share their concerns and questions⁷. It is unclear why there is such a discrepancy. However, the current NIHR funded MATREP study, which is exploring parents' experiences of reviews and investigations, may shed light on the discrepancy between what is reported by clinical staff in the PMRT tool and parents' lived experience⁸.

Good engagement with parents and families will improve the quality of their review from which they will benefit directly. Future adverse safety events and deaths will be prevented following the implementation of relevant quality improvement actions identified in high quality reviews. Free online training provided by the PMRT collaboration, including how to deliver meaningful parent engagement, has been avail able for health care professionals using the PMRT since the start of 2024. Sands have developed training and resources to support clinical staff having discussions with parents about reviews⁹. Sands also have guidance for parents to support them in raising concerns and to help them understand the various review processes, including the PMRT review that may occur when a baby dies (Appendix D). To further support the conduct of high quality PMRT reviews, from early 2025, the PMRT collaboration will be running online, on-demand, training for staff to supplement the written guidance on the PMRT website.

When parents have provided feedback, communication issues, feeling unsupported and not being listened to continue to be reported by parents. The majority of parents who have questions ask either specific or general questions about their care or the reason for the death of their baby. Reassurance was sought by some parents that their actions, or a failure to do something, did not lead to their baby's death. Encouragingly a quarter provided positive comments about their care and the staff caring for them, this is a

- 8 MATREP | The University of Manchester
- 9 www.sands.org.uk/reviews

⁶ www.npeu.ox.ac.uk/pmrt/parent-engagement-materials

⁷ Stillbirth and neonatal death charity (Sands). Bereaved parents' experience of care survey report. Sands, 2023. www.sands.org.uk/sites/default/ files/Bereaved_Parents_Experience_of_Care_Report_2023_digital.pdf (accessed 27th Oct 2024)

higher proportion than in the previous report. The number of parents who had questions indicates that communication with parents is an ongoing process, not an event and that ongoing communication is important for many parents.

The ability to conduct a thorough, robust and systematic review of all stages of the pregnancy and neonatal care journey requires the involvement of health professionals who deliver care at all the stages of care. Conducting a high quality review is a multidisciplinary activity, which ideally also involves someone external to the organisation who can provide the 'fresh eyes' and challenge of an independent professional. There has been a steady improvement in the number of healthcare professionals involved in review teams and notably, over four fifths of reviews of neonatal deaths now involve a neonatologist or paediatrician and about half involve a neonatal nurse. Just over 50% of reviews also now involve a healthcare professional external to the trust/ health board, which also represents a steady increase from previous years. One of the criticisms of PMRT reviews is that they are conducted by the organisations who provided the care being reviewed and who are thus, in essence, 'marking their own homework'. Ideally, all reviews would benefit from the presence of an appropriately qualified and independent senior external clinician, but without additional resources, this is unlikely to be achieved in the near future. We have updated the PMRT system to enable the local PMRT teams to specify more clearly whether an external reviewer was present for the multidisciplinary review meeting.

Just over a third of reviews benefited from administrative support, which is a slight improvement from the previous year but is certainly far from ideal. Administrative support can help ensure reviews are timely and have all the relevant information available at the meeting, the latter being a task that will otherwise fall to a clinical member of the team. The presence of members of the risk management and governance teams is also essential to ensure that learning from reviews is translated into actionable plans, which are implemented and subsequently audited. These team members were present for just over three-quarters of reviews representing only a marginal increase from the previous year. Similarly, the proportion of reviews with a member of the bereavement team present, at less than two thirds, is unchanged from the previous report. This is also far from ideal given the potential impact that poor bereavement care can have on a family's future psychosocial wellbeing. The expectation is that during the review process the bereavement midwife will also advocate on behalf of the parents ensuring that their questions, concerns and comments are addressed. It also appears that when the bereavement team are involved, in some organisations they are expected to manage the PMRT process. We strongly advise against this since the role of the bereavement team member(s) is one of advocacy, and not to take responsibility for the PMRT review process (Appendix B).

The issues with care identified in this report are largely focused around the same areas as in previous reports which for antenatal care include mothers booking late or arriving in labour unbooked, inadequate surveillance of fetal growth and inadequate assessment and management of reduced fetal movements; assessment of maternal risk status and staffing issues during labour and birth; thermal and respiratory management once the baby has been born; and the quality of documentation. These issues should therefore remain a focus of quality improvement activities, two of which in England, for example, will include the full implementation of the Saving Babies Lives Care Bundle version 3.5 The proportion of reviews identifying assessment of the need for antenatal aspirin as an issue has decreased substantially overtime and of note in the survey of QI activities the introduction of system level actions to improve screening was mentioned by multiple respondents. Whilst not incontrovertible proof, this suggests that actions taken following PMRT findings are having an impact on the future quality of care provided.

The single most common issue with investigations carried out after the baby has died continues to be that when a post-mortem was requested, babies had to be transferred to another hospital for this examination. The proportion of reviews where this was mentioned has remained unchanged at about a quarter since 2020-2021. The need for transfer relates to access to specialist perinatal pathology services, which are largely centralised due to the small number of pathologists now available with these skills. Transfer may be distressing for parents and, whilst this should not necessarily be the case, in some places anecdotal reports suggest that it lengthens their wait for the review findings.

The inadequate location and quality of the bereavement suite continues to be highlighted for about 1 in 10 parents which clearly requires attention. Some parents may wish to take their baby home, others may not, but everyone has a right to an informed choice and may need help to decide what to do. In the absence of support and practical help the ability to take their baby home was not available for 18% of parents, the same as in the previous report, thus there is still room for improvement. Importantly, the ability of PMRT review teams to review the quality of bereavement care was adversely affected by not being able to access bereavement care notes which anecdotally appear to be located separately from the general maternity notes in many places.

Overall, 93% (19 out of 20) of reviews had at least one issue with care identified and for 34% (about 6 out of 20) of reviews, this was judged by the review teams to have been relevant to the outcome for the baby. The latter is an increase from 20% (4 out of 20) of reviews in the previous report. In this report, we present the overall holistic grading of care by the review panel at different stages along the care pathway. Over time, there has been a small but steady decline in the proportion of reviews where the care has been graded as A, ('no issues with care identified') with a commensurate increase in the proportion with grades C ('issues which may have made a difference to the outcome') and D ('issues which were likely to have made a difference to the outcome') other than for bereavement care where the commensurate increase has been in the proportion graded B ('issues that would have made no difference to the outcome'). In the presence of generally decreasing perinatal mortality rates, these changes seems likely to be a result of review teams taking an increasingly self-critical approach to the care their organisations provided, more reviews having an external member present and seeking to improve future care, rather than being a result of poorer care in general being provided. If this is the case then this is a positive development.

Previously, the presence of an external professional was associated with a change in the distribution of grades with a greater proportion of B, C, and D grades. This trend has continued, although the differences are quite small, and may be part of a general trend to being more self-critical and improving the learning from the reviews being conducted.

The final important step in any review is to identify which issues need action to improve future care. It is heartening to now see a substantial proportion of actions which are 'strong' or 'intermediate' in strength and resulting in system level changes which do not rely solely on the actions of individuals for implementation. Acknowledging that not all actions to deal with issues can be strong or even of intermediate strength and in most cases strong actions should be accompanied with weaker actions, with over half of all actions now being of this strength, the direction of travel is encouraging.

There is no one single over-riding issue with care, relevant to the outcome for the baby that, if changed, would have a substantial impact on the perinatal mortality rate in any organisation. This underlines the fact that multiple, incremental and sustained improvements across all aspects of care are required to make a substantial difference to the perinatal mortality rate of individual trusts and health boards, and nationally. Once a review is completed and improvement actions planned, the PMRT review process closes. It

is therefore not possible from the PMRT data to identify which actions were actually taken forward into quality improvement (QI) activities. As a consequence, we are reliant on findings from a survey we under-took this year (2024) to identify examples of QI activities which trust and health boards who responded have undertaken. Not surprisingly, many of them deal with the most common issues with care identified in reviews. We have included examples of QI activities in the body of the report and an extended list is available on the PMRT website (https://www.npeu.ox.ac.uk/pmrt/reports). These provide a useful list of activities that other organisations may benefit from implementing. Trusts and health board s might usefully review the list of issues that led to these QI activities against the list of their own issues with care which they can generate from the summary report function in the PMRT. The QI activities outlined in this report may provide ideas of how to improve care where organisations have similar issues with care.

Recommendations

1. Evaluate the approach to parent engagement in reviews, ensure staff are trained and use the available PMRT Parent Engagement materials, particularly in trusts and health boards where fewer parents are engaged with the review process.

Action: Trusts and health boards, staff caring for bereaved parents, service commissioners

2. Provide adequate resourcing of PMRT review teams, including administrative support, and risk and governance team members.

Action: Trusts and health boards, service commissioners

3. Provide adequate resourcing to ensure the involvement of independent external clinicians in review teams.

Action: Service commissioners

4. Use the local PMRT summary reports and this national report as the basis to prioritise resources for key aspects of care and quality improvement activities identified as requiring action.

Action: Trusts and Health Boards, Service Commissioners, regional/network support systems, Governments

5. Improve service quality improvement activities implemented as a consequence of reviews by developing 'strong' actions targeted at system level changes and audit their implementation and impact. Review and implement relevant examples of 'strong' quality improvement activities in this report to improve service delivery.

Action: PMRT review teams, governance teams in Trusts and Health Boards, Service Commis sioner

Appendices

Appendix A - Parent engagement materials

A working group, which included parents and clinicians, developed a set of resources to support parent engagement with reviews. These were refreshed in 2024 and are available to download from the PMRT website

www.npeu.ox.ac.uk/pmrt/parent-engagement-materials

Appendix B - Recommended composition of review teams and roles

An **external panel member** should be a relevant senior clinician who works in a hospital external to the trust and health board undertaking the review. Their role is participate in the review panel to provide a 'fresh eyes', independent and robust view of the care provided. This may involve challenging the care that was provided by the trust/health board when the death occurred. The external should be senior enough to provide challenge where appropriate and should actively participate in the discussions about the care.

The role of the bereavement team member(s) is to contribute to the review of care and to advocate on behalf of the parents by presenting their questions, concerns and comments; they should not be required to take responsibility for the PMRT review process unless they are specifically employed to do so.

In England, as part of Safety Action 7 of the year 6 Maternity Incentive Scheme (MIS), trusts are required to work with their LMNS/ICB to ensure a funded, user-led Maternity and Neonatal Voices Partnership (MNVP) is in place which is in line with the Delivery Planⁱ and MNVP Guidanceⁱⁱ (published November 2023). As part of the year 6 MIS evidence requirements, trusts need to provide terms of reference for safety and governance meetings showing the MNVP Lead as a member. The meetings listed include PMRT review meetings. The role of the MNVP Lead in PMRT meetings is to provide the 'parent voice'. This is different from the role of the Bereavement Midwife who is there to advocate on behalf of the specific parents the death of whose baby is under discussion.

Of note: Although the MNVP member may not be employed directly by the Trust they should not be regarded as, nor documented as, an 'external' member. They are present to represent the wider parent voice.

i. www.england.nhs.uk/publication/three-year-delivery-plan-for-maternity-and-neonatal-services/

ii www.england.nhs.uk/long-read/maternity-and-neonatal-voices-partnership-guidance/



Appendix C - Action plan strength

The US Veterans Affairs root cause analysis tools defines the strength of an action by describing how well the action would eliminate human error.

Strong actions are system level changes that remove the reliance on individuals to choose the correct action. They use standardisation and permanent physical or digital designs to eliminate human error and are sometime referred to as 'forcing' actions.

An example of a strong action is the development of a process for ensuing the systematic assessment of all women for the need for aspirin for pre-eclampsia prophylaxis and including this as a mandatory item in the electronic patient record.

Intermediate actions are those actions that put systems in place, but those systems still require individuals to make choices about the correct actions to take without any controls in place.

An example of an intermediate action is a major review, which led to a new staffing model and a newly appointed Lead for Triage and Induction.

Weak actions involve reminders to individuals for action and training which require individuals to use the training to make choices about the correct actions to take and do not put any controls in place. They are often single activities without repetition, which take no account of the fact that new staff are appointed. They can also involve debrief discussions with an individual involved in a patient safety incident. This will have no effect on the clinical behaviour of other members of staff.

An example of a weak action is the distribution of a communication to maternity staff regarding the necessity for intrapartum antibiotics in preterm labour and the importance of this.

See: US Department of Veterans Affairs. Root Cause Analysis Tools. VA National Center for Patient Safety. REV.02.26.2015. (Pgs 26-29) RCA Step by Step Guide REV 07.01.2016 (va.gov)

Appendix D - Sands parent resources

Free online training in delivering meaningful parent engagement is available for health care professionals from Sands:

https://training.sands.org.uk/courses-and-booking/open-access/

Sands survey of members' experiences of reviews and the 'Listening Project' of marginalised groups are available at:

https://ww.sands.org.uk/sands-parent-surveys-and-reports

Sands guidance for parents - 'How to raise concerns, give feedback or make a complaint' is available at:

https://www.sands.org.uk/sites/default/files/Complaints_Raising_Concerns_Feedback_Aug_2023.pdf?_ gl=1*olti7b*_ga*NjM3NjA1MDIwLjE2OTc1Mzg5Nzc.*_ga_RXE8QR4HHG*MTY5OTAwOTExOC4zLjE uMTY5OTAwOTQ5OC41NS4wLjA

Sands information for parents - 'Understanding why your baby died' is available at:

https://www.sands.org.uk/understanding-why-your-baby-died

Appendix E - PMRT process for parents

Perinatal Mortality Review Tool (PMRT) Process for Parents

Receive PMRT information

- You will be told who your key contact is and given information about bereavement care.
- You should be given written information about the PMRT with a feedback form and details about how to provide feedback about your care and your baby's care. This might come in the post or by email.
- You can speak to your key contact by email, phone, or face-to-face, depending on what you prefer. You do not have to provide any feedback or ask any questions if you would prefer not to.
- Your feedback will be reviewed at the PMRT meeting. Anything urgent will be passed to the safety team. If you have decided not to give any feedback, the team will be updated.
- Your key contact will keep in touch and let you know about the progress and timescales of the PMRT unless you ask not to be. You can always get back in touch later if you prefer.



PMRT review meeting takes place

• Healthcare workers will meet to review care. An external reviewer may also be invited. There might need to be more than one review meeting.

• Your questions, concerns, and feedback will be discussed and input to the PMRT system and report. If you provided any questions, they will be answered.



PMRT report is drafted

 Plans are made to complete any actions for changes in care which have been found and to make sure staff have support to make changes where needed.

- Any findings to improve care for future mothers, babies and families will be shared with healthcare workers and fed back to the quality and safety team if appropriate.
- Guidelines and processes might be changed depending on review findings.

Report summary sent

- •You will be told when the review meeting has taken place and offered a meeting to discuss the review, unless you have asked not to be kept up-to-date. You can change your mind at any time.
- •You will receive a letter or report explaining the review and findings unless you said you do not want one.
- The review will be complete but you can get back in touch with any thoughts or questions. There is no time limit.



After the PMRT is complete

- The PMRT team uses the information kept in the PMRT system to write an annual report and other reports about how the PMRT is used and the findings from across the UK. The information published does not identify any individual mothers, babies and families.
- The PMRT reports are shared with midwives, doctors, researchers, collaborators, the Department of Health and Social Care and people working in devolved Government so that everyone can learn how to make improvements in care.
- If you have any other questions or comments, you can get in touch with your key contact, or call Sands on 0808 164 3332

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