

National Perinatal Mortality Review Tool



Learning from Standardised Reviews When Babies Die

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Third Annual Report

Technical Paper



October 2021



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HQIP is led by a consortium of the Academy of Medical Royal Colleges, the Royal College of Nursing and National Voices. Its aim is to promote quality improvement in patient outcomes, and in particular, to increase the impact that clinical audit, outcome review programmes and registries have on healthcare quality in England and Wales.

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Glossary

CDOP	Child Death Overview Panel (England)
CTG	Cardiotocograph
DH	Department of Health
DNA	Did not attend (appointment)
FIGO	International Federation of Gynecology and Obstetrics
GDM	Gestational diabetes mellitus
NCMD	National Child Mortality Database
NPSA	National Patient Safety Authority
MBRRACE-UK	The collaboration established to deliver the MNI-CORP
MNI-CORP	Maternal, Newborn and Infant Clinical Outcome Review Programme
MSU	Mid-stream sample of urine
PMRT	Perinatal Mortality Review Tool
Sands	Stillbirth and neonatal death charity

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1. Introduction and development of the national Perinatal Mortality Review Tool (PMRT)

The concept of developing a national Perinatal Mortality Review Tool (PMRT) has its origins at a March 2012 Stillbirth Prevention Summit held with over 50 stakeholders by Sands, the stillbirth and neonatal death charity, which represent the voices of thousands of families who's baby has died in the UK. The need to improve the review of care when babies die, and thus the development of a perinatal mortality review tool, was identified as one of several streams of work with the goal of reducing the incidence of stillbirth in the UK. The Department of Health for England (DH) agreed to support Sands in this endeavour by supporting work to define a robust review process for all perinatal deaths.

Dr Tracey Johnston, Consultant Obstetrician at the Birmingham Women's and Children's NHS Foundation Trust, was asked to chair a DH/Sands Task and Finish Group given the remit of taking forward the work to develop a national perinatal mortality review toolⁱ. Along with undertaking a survey of practice, the group developed an aspirational vision for a perinatal mortality review tool (PMRT) (Box 1) and a set of principles for the purpose and function of a national PMRT (Box 2). From this set of principles they developed a list of data items with the intention that these items would form the basis of the tool.

Box 1: Vision for a National Perinatal Mortality Review Tool*

- All perinatal deaths will be reviewed in an objective, robust and standardised way;
- Parents will receive as full an explanation as possible as to why their baby died;
- We will learn more about why babies die;
- We will be able to target resources towards causes and address any shortfalls in care at local, network and national levels;
- Learning can be shared;
- Fewer babies will be stillborn or die in the neonatal period and mortality rates will fall.

*Vision of the DH/Sands Task and Finish Group

Following this work, submitted to the DH in March 2014, several national enquiries highlighted yet again the need for improved reviews when deaths occur. The Kirkup Report of the Morecambe Bay Investigation published in March 2015 highlighted that the care and events surrounding both stillbirth and neonatal deaths at Furness General Hospital were either inadequately scrutinised or sometimes not investigated at all [1]. As a result lessons following perinatal deaths were not always learnt. The MBRRACE-UK 2015 Confidential Enquiry of Term, Singleton, Normally Formed, Antepartum Stillbirths in 2013 found that for 60% of the deaths improvements in care were identified which may have made a difference to the outcome, yet there was only evidence that a review of the care provided had been undertaken for a quarter of the deaths [2]. The recommendations by Kirkup set in train a series of responses including the commissioning by the Department of Health and Social Care (England), with Scotland and Wales, of a national PMRT to improve and standardise the quality of local reviews when perinatal deaths occur.

The Healthcare Quality Improvement Partnership (HQIP) was asked to carry out an open, competitive commissioning process for the development and implementation of a national PMRT on behalf of the English, Scottish and Welsh Governments. Tendering commenced in March 2016 and concluded in June 2016 with the appointment of the MBRRACE-UK/PMRT collaboration. The contract award was delayed by external events and work started on developing the PMRT in February 2017.

ⁱ **DH/Sands Task and Finish Group representatives:** Dr Tracey Johnston (chair) and representatives from: Bliss the premature baby charity, British Association of Perinatal Medicine, British Maternal Fetal Medicine Society, Department of Health (England), MBRRACE-UK, NHS Litigation Authority, NHS Strategic Network, Improving Quality, Manchester, Parent representatives, Midwifery Research, Perinatal Institute, Royal College of Midwives, Royal College of Obstetricians and Gynaecologists, Royal College of Pathologists, South West Midlands Newborn Network, the stillbirth and neonatal death charity Sands, the Stillbirth Clinical Studies Group and the Devolved Nations. A number of individuals were invited to provide their specific expertise.

Box 2: Principles for a National Perinatal Mortality Review Tool identified by the DH/Sands Task and Finish Group

- There should be comprehensive and robust review of all perinatal deaths from 22⁺⁰ weeks gestation until 28 days after birth; excluding termination of pregnancy and those with a birth weight <500g;
- Such reviews should be conducted using a standardised, nationally accepted tool, ideally web-based, that includes a system for grading quality of care linked to outcomes;
- A multidisciplinary group should review each case at a meeting where time is set aside for doing the work;
- There should be scope for parental input into the process from the beginning;
- The outcome of individual reviews should be shared with the parents/families in a sensitive and timely manner;
- There should be a quality control/review process with external peer review;
- Action plans generated by such reviews must be implemented and monitored;
- There should be biannual reporting to the relevant hospital committee, with evidence of organisational learning;
- These reports should feed up regionally and nationally to allow benchmarking and publication of results, to ensure national learning.

2. The conceptual basis underpinning the PMRT

When developing the tool, the underlying concept of the PMRT was based on the vision laid out by the Task and Finish Group (Box 1), placing at its core the fundamental aim of ensuring objective, robust, standardised reviews to provide answers, where possible, for bereaved parents about why their baby died. A second, but nonetheless important, aim was to ensure learning from past events in order to improve care and ultimately prevent future deaths.

In order to achieve these aims a multi-dimensional approach to review underpinned the design of the tool encompassing the following:

- Embedding parents' views of care by placing them at the heart of the review process from the outset;
- Providing parents with the best available explanation of why their baby died by generating standardised clinical reports to support full and structured discussions between health professionals and bereaved parents;
- Achieving robust, standardised reflective perspectives of care at all stages of the pregnancy and postnatal pathway, based on systematically recorded relevant clinical and sociodemographic information;
- Providing opportunities to improve care by reinforcing national standards and guidelines;
- Improving local care by generating action plans which focus on system level changes rather than changes at the individual level;
- Ensuring shared learning to prevent future deaths by combining the findings from individual reviews into reports both at the Trust and Health Board level, and nationally.

The PMRT has been designed as an integrated system within the MBRRACE-UK perinatal mortality surveillance data collection system. This enables notification of a death by the provision of demographic and key clinical descriptors that are common to both perinatal surveillance and the PMRT and thus avoids duplicate data entry. Once the notification of the death is complete, users are encouraged to complete the MBRRACE-UK surveillance data collection before starting a review as information common to both the surveillance and the PMRT are cross-populated from the MBRRACE-UK surveillance data collection into the PMRT. Information does not cross-populate from the PMRT to the surveillance data collection; this is by design in order to encourage prompt completion of the surveillance data.

3. Findings from the PMRT reviews

The deaths for which the PMRT is designed to support review were defined by the MBRRACE-UK/PMRT collaborators (Box 3).

Explicitly excluded from the PMRT review are deaths as the result of a termination of pregnancy or where the death occurs in the community when the baby was discharged home well. The PMRT can be used to review deaths which fall outside the criteria in Box 3, for example, deaths of babies at <22⁺⁰ weeks' gestation, but not all aspects of care which should be reviewed will necessarily be covered by the tool for these deaths and the PMRT is not recommended for use in reviewing these deaths.

Box 3: Deaths for which the PMRT is designed to support review of care

The PMRT has been designed to support review of the following perinatal deaths:

- Late miscarriages (also referred to as late fetal losses) where the baby is born between 22⁺⁰ and 23⁺⁶ weeks of pregnancy showing no signs of life;
- All stillbirths where the baby is born from 24⁺⁰ gestational weeks showing no signs of life;
- All neonatal deaths where the baby is born alive from 22⁺⁰ weeks and dies up to 28 days after birth;
- Post-neonatal deaths where the baby is born alive from 22⁺⁰ weeks and dies after 28 days after birth following neonatal care; the baby may have died in hospital, a hospice or at home following palliative care.

The PMRT does not support the review of perinatal deaths where the death meets the criteria above but:

- The death follows a legal termination of pregnancy;
- The baby was discharged home well, had not received neonatal care but died up to 28 days after birth;
- The baby was discharged home well, had not received neonatal care but died after 28 days after birth.

4. The importance of parent engagement

Parents whose baby has died have the greatest stake in understanding what happened and why their baby died; they can also offer extremely helpful insights into the care they received. Engaging bereaved parents in the review process and including their views and any concerns and/or questions they have about their or their baby's care will improve the quality of the review and ensure that from the outset the review addresses their questions. Parents, particularly mothers, have a unique perspective on everything that happened to them and their baby, being the only people actually present for the entirety of the pregnancy. For this reason the first set of care-related questions in the PMRT addresses questions around engagement with parents and any questions and concerns they have.

Engaging bereaved parents in the review process does not mean having the parents present at the review. Engagement emphasises the importance of informing them the review is taking place and giving them the opportunity to share their views or any questions or concerns they have about their or their baby's care so that these can be specifically addressed by the review process.

During 2018 materials were developed to support staff in Trusts and Health Boards to meaningfully engage with bereaved parents. The resources were developed by a multidisciplinary group from the MBRRACE-UK/ PMRT collaboration that included bereaved parents, and are based on the published findings from the PARENTS and PARENTS2 studies [3,4,5] and the 'Being Open' process for maternity services in Scotland. www.npeu.ox.ac.uk/pmrt/parent-engagement-materials

5. The PMRT development process

A working group (see acknowledgements in the main annual report) was established to generate the contents of the PMRT with our starting point as the data items in the spreadsheet developed by the DH/Sands Task and Finish Group. The working group met for nine one-day meetings during 2017 with a further meeting to discuss the contents of the reports generated for individual reviews; not all members were present for all meetings. The group worked through the pathway of care from pre-conception to the death, and bereavement and follow-up investigations, in order to develop the review questions and the issues generated when the care provided was not appropriate.

All elements of care where there are existing national or relevant international (mainly FIGO) standards and guidelines were identified during the process of review question development. 'Tool tips' (pop-up dialogue boxes within the tool) containing the national guidance were drafted as question development proceeded. Following the initial development and incorporation into the PMRT the 'tool tips' have been edited as updated guidance has been released. New tool tips have been written as new guidance has been published.

The grading of care was discussed and agreed by the MBRRACE-UK/PMRT Collaborator group. The National Patient Safety Agency contributory factors framework [6] was incorporated into the tool to enable review teams to use a common framework to document the factors contributing to the issues with care they identified in their reviews.

The development of the web-based tool used agile software development methods, with the programming being carried out contemporaneously with the question development process. Further refinement of questions, issue generation and the structure of the questions in the tool followed internal testing and user feedback in the pilot phase, and continued in response to on-going user feedback following the general release. A full formal user survey was carried out in November 2018 and changes were made to the tool in response to user comments. Tool refinement continues as an on-going continuous improvement process and in response to on-going user comments.

6. The contents of the tool and its use

The PMRT provides a systematic approach to reviewing care at each stage of the pregnancy and post-natal pathway. This is achieved by combining the collection of relevant clinical and sociodemographic information derived directly from the medical notes recorded in a robust manner (here referred to as 'Factual Questions') with reflective clinical perspectives of the care to support standardised review of care ('Reflective Questions').

6.1 Reflective questions

During the development phase of the PMRT, the conceptual basis of the PMRT was further elaborated following the philosophy that the PMRT is a 'tool' to support standardised, systematic, robust review of care and not a data collection system; although, as the PMRT is web-based, data are inevitably 'collected'. Following this philosophy the nature of the questions in the tool ask the multidisciplinary team undertaking the review to reflect on and make 'judgements' about the care provided, by presenting the team with questions which are posed in the general form of:

- Given this woman's past history of (e.g. pre-eclampsia) was her care appropriate?
- Was the baby's temperature within an acceptable range when first measured on the neonatal unit?

Where national (or international e.g. FIGO) standards and/or guidelines exist to support the assessment of the quality of specific aspects of care these are embedded in the tool as 'tool tips' alongside the relevant questions. The tool tips are signaled and are accessed by clicking the information icon placed alongside relevant questions. Clicking the information icon opens up a new dialogue box which contains all the relevant available guidance on the particular topic. An example is given in Box 4.

Box 4: An illustration of the presentation within the PMRT in a 'tool tip' of national standards and guidelines relating to the thermal management of newborn babies



6.2 Factual questions

While the review of care questions take the 'reflective' form described above, to ensure that the appropriate aspects of care are considered for each death during the review 'factual' questions precede the reflective questions. The factual questions ensure that only appropriate questions about care are asked. For example, questions about past obstetric history trigger later questions in the tool relevant to past obstetric history to 'open'. These include questions about the management of the current pregnancy given a past history of relevant conditions, for example pre-eclampsia. The inclusion of factual questions avoids the review team being asked to consider questions which do not apply, such as whether care was appropriate based on past obstetric history when this was the woman's first pregnancy.

6.3 Issues with care and contributory factors

The concept of ‘issue’ generation is used for situations where the review team identifies instances where appropriate care had not been provided. For example, if a woman was eligible for gestational diabetes screening and this was not offered, or a baby’s temperature was not within the recommended range on arrival in the neonatal unit, an ‘issue’ with care will be generated. At the end of each review the issues generated within that review are presented as a list. The review team is then asked to select for each issue the factor(s) contributing to the failure to provide appropriate care, using the National Patient Safety Agency Contributory Factors Framework [4].

Following the assignment of contributory factors the review team is then asked to consider, the contribution of each issue in turn, to the outcome using the following options. An issue can be:

- Relevant to the outcome and was managed appropriately;
- Relevant to the outcome, but was not managed appropriately and action is needed to improve future care;
- Not relevant to the outcome in this instance, but action is nevertheless needed to improve future care;
- Not relevant and no action is needed.

An example of an issue which was not relevant to the outcome but action is needed is where a mother met the criteria for screening for diabetes mellitus, but was not offered screening. Whilst the baby died from a cause unrelated to diabetes, a system level action is nevertheless required to ensure that in the future all eligible women are offered gestational diabetes screening.

6.4 Action plans

For each issue which requires action(s), the review team is asked to identify what the future action(s) to improve care should be. All the actions for all the issues are then combined into an Action Plan. A key responsible individual for each action is identified and a timeline for each action is added. We encourage the development of SMART (specific, measurable, achievable, realistic and time-bound) and ‘Strong’ⁱⁱ [7] action plans which focus on systemic organisational solutions rather than focusing on actions involving individual members of staff.

6.5 Grading of care

In the final section of the tool the review team is asked to ‘grade’ the quality of the care provided. In the case of a stillbirth or late miscarriage the following aspects of care are graded:

- Care of the mother and baby up to the point of birth of the baby;
- Care of the mother following confirmation of the death of her baby.

In the case of a baby dying after birth the following aspects of care are graded:

- Care of the mother and baby up to the point of birth of the baby;
- Care of the baby from birth up to the death of the baby;
- Care of the mother following the death of her baby.

A four level system for grading the care was agreed by the MBRRACE-UK/PMRT Collaborators (Box 5).

Box 5: Categories used to grade the different aspects of care for each death

- A. No issues with care identified
- B. Care issues that would have made no difference to the outcome
- C. Care issues which may have made a difference to the outcome
- D. Care issues which were likely to have made a difference to the outcome

ⁱⁱ Strong actions are system changes which 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 sometimes referred to as ‘forcing actions’.

6.6 Generation of individual review reports and action plans

Once a review has been completed and the responses validated (to ensure that all relevant questions are complete) a report of the review can be generated. The report automatically incorporates the answers to all the relevant questions within the tool. During the course of the review the review team can make notes about specific aspects of care within the PMRT. These notes are incorporated into the report as editable text which allows the review team to expand their notes into narrative prose and provide more detail than is possible by the automatically generated responses.

The action plans are also completed at this stage of report generation with the addition of implementation plans including identifying the individuals responsible and timelines for each action. The action plans from individual reports can also be downloaded as an Excel spreadsheet. This is to allow inclusion of the action plan in the Trust/Health Board governance systems.

Finally, the completed report can be downloaded, which is referred to as 'published', in a PDF format which can be both saved electronically and printed out for inclusion in the medical records in preparation for discussion with parents at their follow-up appointment. The report, which is highly clinical, can be used as both the basis of the discussion with parents and also for writing a letter to parents after their follow-up appointment as importantly there is the opportunity to include a management plan for any future pregnancies.

Importantly the report as produced from the PMRT is written in a technical clinical format which is not suitable for giving to parents without either a verbal explanation or a written explanation in plain English. Guidance on transferring this technical clinical report into a plain English version is provided as part of the PMRT Parent Engagement Resources (www.npeu.ox.ac.uk/pmrt/parent-engagement-materials).

6.7 Generation of summary reports

There is also a function available to Trust/Health Board users to generate summary reports which cumulate information from reviews carried out in their organisation over a period of time. This enables issues which are repeated through a number of reviews to be identified alongside summary information about the deaths. PMRT registered users can download a summary report any time they wish and the period covered is defined by the user when they download the report. The summary reports can be used for many purposes including quarterly or half yearly reporting to the management board of the Trust/Health Board.

It is also possible for users to download a limited summary dataset as an Excel spreadsheet. Again this is for a user defined period and allows additional local analysis to support the production of summary reports.

6.8 Using the tool in practice

Guidance is provided on how to use the tool in practice. It is strongly recommended that the reviews are carried out by multidisciplinary teams and guidance is provided on the constitution of such teams, together with a template of terms of reference. Advice is also provided on how to incorporate the tool into the process of review, which includes ensuring that prior to review of a particular death some information is pre-populated into the PMRT, first by completing the MBRRACE-UK surveillance information for that death and second by completing the factual questions in the PMRT. Some of these questions can be completed by administrative support staff and some will need input from a staff member with a clinical background. Prior to the main review meeting some organisations have clinical staff who will carry out a pre-review which will speed things up during the actual review meeting; for example, by adding relevant information into the notes section of the tool. This guidance is provided in a guidance document and also as a slide set (www.npeu.ox.ac.uk/pmrt/implementation-support).

7. Approvals and incentives to encourage the use of the PMRT

Review of care when an adverse outcome, including a death, occurs is a standard part of clinical care. For any parent, the death of their baby is an adverse outcome, regardless of whether it might have been prevented or not. It is a General Medical Council requirement of 'Good Medical Practice', section 22(a), that all doctors take part in regular reviews and audits of their work [8]. As part of standard care it is also good practice, for the reasons outlined above, to explain to parents that a review of their care and that of their baby will be carried out.

The use of the PMRT to carry out the reviews involves the processing and storage of confidential personal and health data on the MBRRACE-UK/PMRT servers. A legal basis is required to enable this processing and storage to occur.

In discussion with our parent, patient and public stakeholder group it was concluded that seeking the consent of parents to use the PMRT to carry out the review and thus to store their data within the MBRRACE-UK/PMRT system would be burdensome for parents at the time of their bereavement when they are often in shock and absorbing lots of new information. On this basis an application was made to the Confidentiality Advisory Group of the Health Research Authority (for England and Wales) for 'section 251 approval' to set aside the common law duty of confidence for the purpose of carrying out reviews using the PMRT. Approval was granted in October 2017: 17/CAG/0150. Annual reviews have been submitted since to enable the approval to remain current. A similar application was made to the Public Benefit and Privacy Panel for Health and Social Care (PBPP) in Scotland and approved in March 2018: 1718-0249. The PMRT was originally not commissioned for use in Northern Ireland. In autumn 2019 Northern Ireland was included. The legal basis for the use of the PMRT in Northern Ireland is parental consent.

The legal basis for the PMRT activity under the Data Protection Act (2018) is:

Article 6 (1) (e) - processing is necessary for the performance of a task carried out in the public interest or in the exercise of official authority vested in the data controller*.

and

Article 9 (2) (i) - processing is necessary for reasons of public interest in the area of public health, in ensuring high standards of quality and safety of health care.

*The Healthcare Quality Improvement Partnership which commissions the PMRT is the data controller

The expectation is that all Trusts and Health Boards in England, Wales, Scotland and Northern Ireland will use the PMRT to review their perinatal deaths and the funders encourage this to happen. An added incentive was introduced in England as part of the NHS Resolution Clinical Negligence Scheme for Trusts (CNST) Maternity Incentives Scheme (MIS). The scheme incorporates 10 actions to support maternity safety that Trusts are expected to comply with to avoid a financial penalty. The first safety action for year one (2018) to the current year four of the scheme (2021-2022) inclusive involves use of the PMRT to review all eligible perinatal deaths [9].

8. Future plans for development of the PMRT

The tool is constantly under review and is updated regularly to refine the questions (often in response to user requests), improve the flow of the questions and update the national guidance within the tool.

A new development released in June 2020 allows Trusts/Health Boards to 'assign' a review to any other organisation who provided parts of the care for the mother and baby so that they can review the care they provided. Any issues with care identified are 'owned' by the organisation that generates them and a single report is produced which includes all elements of the reviews conducted. Production of a single report is designed to avoid parents being given contradictory information and advice. As of 1st Sept 2021 68% of reviews, where care was provided in more than one location, have been assigned using this function enabling review by all organisations involved in the care. This represents 15% of all reviews carried out using the PMRT since this function was made available.

In England, notification and the findings from reviews of neonatal deaths also need to be submitted to the local Child Death Overview Panel (CDOP) and the recently established National Child Mortality Database (NCMD) [10]. Work continues between the MBRRACE-UK/PMRT team and the NCMD team to develop a single process to enable notifications of neonatal deaths to the local CDOP to be generated and forwarded from the MBRRACE-UK/PMRT notification and the information from the review using the PMRT to be forwarded directly to the local CDOP and NCMD without the need for a separate process of data provision. Of note, the current 'Working Together to Safeguard Children' guidance (which has legal force) specifies that a local review of all neonatal deaths must to be carried out by the organisation where the baby died and the review should be carried out using the PMRT [11]. Following delays due to COVID-19 related priorities release of these new functions are anticipated in early 2022.

Future developments are planned to continue to reduce duplication of data provision and reducing the burden of review for example, for multiple births where both/all the babies die, by cross-population of the pregnancy care information.

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