Written evidence submitted by MBRRACE-UK (PSN0002)

Area considered: Maternity care and leadership

Specific evidence addressed:

- Perinatal and maternal mortality surveillance data post 2021
- Data from national scrutiny of perinatal and maternity deaths
- Examples of independent scrutiny of perinatal deaths and maternal deaths and its application at local, regional and national levels
- Evidence of adoption and quality of review

1. Summary

The most recent data from MBRRACE-UK surveillance shows increased extended perinatal mortality rates (2021) and increased maternal mortality rates (2020-22) in the UK. Independent national investigations (Confidential Enquiries) into maternal and perinatal deaths and maternal severe morbidities conducted by MBRRACE-UK continue to demonstrate improvements to care which may have made a difference to the outcome of care for women and/or their babies. There has been an increase in the proportion of local reviews conducted using the national Perinatal Mortality Review Tool, with an increasing proportion of reviews involving a multi-disciplinary team and an increasing proportion including an external independent member of the review group. Most parents of babies whose care was reviewed using the national Perinatal Mortality Review Tool were told that a review of their baby's care would be taking place. The most recent confidential enquiry into perinatal deaths, published in December 2023, reported that the hospital reviews, most of which were conducted using the Perinatal Mortality Review Tool, were more positive than the conclusions reached by the independent external confidential enquiry panels.

2. Background

1.1 The MBRRACE-UK collaboration

Mothers and Babies: Reducing Risk through Audits and Confidential Enquiries across the UK (MBRRACE-UK) is the collaboration appointed by the Healthcare Quality Improvement Partnership to run the Maternal, Newborn and Infant Clinical Outcome Review Programme. The collaboration is led from the National Perinatal Epidemiology Unit based at the University of Oxford with additional collaborations at the Universities of Leicester and Birmingham, Newcastle-upon-Tyne Hospitals NHS Foundation Trust, Chelsea and Westminster Hospital NHS Foundation Trust and the stillbirth and neonatal death charity, Sands.

As part of the Maternal, Newborn and Infant Clinical Outcome Review Programme, MBRRACE-UK investigates the care of all women who die during pregnancy and up to one year after the end of pregnancy, and selected cases of severe maternal morbidity during or after pregnancy in the UK through routine surveillance and confidential enquiries. The collaboration also undertakes surveillance of all stillbirths, late fetal losses and neonatal deaths (deaths up to 28 days of age) in the UK, alongside confidential enquiries into the care of specific samples of babies who die or have serious morbidities. Confidential enquiries are national, independent investigations into the circumstances around each death and the care received prior to each death.

MBRRACE-UK has published annual reports detailing the findings of national maternal and perinatal death surveillance, together with annual reports of maternal confidential enquiries and bi-annual reports of perinatal confidential enquiries.

More detail is available at: https://www.npeu.ox.ac.uk/mbrrace-uk

1.2 The Perinatal Mortality Review Tool (PMRT)

MBRRACE-UK is also part of the collaboration which developed and established a national standardised Perinatal Mortality Review Tool. The Perinatal Mortality Review Tool was developed during 2017 and released in January 2018. The tool is provided free to all UK NHS maternity and neonatal units to support high quality standardised perinatal reviews on the principle of 'review once, review well'. The tool provides maternity and neonatal units with a series of questions to enable units to:

- Conduct systematic, multidisciplinary, high-quality reviews of the circumstances and care leading up to and surrounding each late fetal loss (late miscarriage at 22-23 weeks' gestation), stillbirth (from 24 weeks gestation) and neonatal death (babies who are born alive and die up to and including 28 days after birth), and the deaths of babies who die in the post-neonatal period (babies who die after 28 days after birth) having received neonatal care.
- Undertake active communication with parents to ensure they are told that a review of their care and that of their baby will be carried out and how they can contribute to the process.
- Conduct a structured process of review, learning, reporting and actions to improve future care.
- Come to a clear understanding of why each baby died, accepting that this may not always be possible even when full clinical investigations have been undertaken; this involves a grading of the care provided.
- Produce of a clinical report for inclusion in the medical notes.
- Produce a report for parents which includes a meaningful, plain English explanation of why their baby died and whether, with different actions, the death of their baby might have been prevented.
- To identify broader learning to improve care for the future including preventing future perinatal deaths.

More detail is available at: https://www.npeu.ox.ac.uk/pmrt

3. Specific evidence

1.3 Perinatal and maternal mortality surveillance data post 2021

1.3.1 Perinatal Mortality

The latest perinatal mortality data released by MBRRACE-UK is for perinatal deaths for births from 1 January 2021 to 31 December 2021. After seven years of year-on-year reduction, extended perinatal mortality rates increased in the UK in 2021 to 5.19 per 1000 total births compared to 4.85 per 1000 in 2020. This comprised 3.54 stillbirths per 1,000 total births (3.33 in 2020) and 1.65 neonatal deaths per 1,000 live births (1.53 in 2020). Increased rates were observed for both stillbirths and neonatal deaths in almost all regions in the UK. The only region that did not see an increase in the rate of stillbirths from 2020 to 2021 was Scotland. All regions had an increase in the rate of neonatal death.

Stillbirth and neonatal mortality rates increased in almost all gestational age groups. Late fetal loss and stillbirth rates increased in 2021 compared with 2020 for all gestational age groups, except for babies born between 37 and 41 completed weeks' gestational age. Neonatal mortality rates increased for all gestational age groups. The largest increase for stillbirth rates was in the 28 to 31 week gestational age group and for neonatal mortality rates was in was in the 24 to 27 week gestational age group. Preterm births occurring before 37 weeks contribute to account for a large proportion of stillbirths and neonatal deaths. The most common causes of stillbirth were due to placental, congenital anomalies, cord problems and infection. A large proportion of stillbirths still have an unknown cause of death. The most common causes of neonatal death were congenital anomalies, extreme prematurity, neurological, cardio-respiratory and infection.

Ethnic and socioeconomic inequalities persist in stillbirth and neonatal mortality rates. Babies born to mothers living in the most deprived areas and babies of Black and Asian ethnic backgrounds having higher rates than those in the least deprived areas or from White ethnic backgrounds, respectively.

There continues to be wide variation in the stabilised and adjusted stillbirth and neonatal mortality rates in different organisations compared to comparator group averages.

More information on the findings of perinatal mortality in the UK for 2021 can be found in the published report available from: https://timms.le.ac.uk/mbrrace-uk-perinatal-mortality/surveillance/.

1.3.2 Maternal Mortality

Preliminary data analysis has been undertaken on maternal mortality data from 2020-22 and will be released by MBRRACE-UK in the form of a data brief on 11th January 2024.

Please note the information provided in this section (1.3.2) is embargoed until 11th January 2024.

The overall maternal death rate in 2020-2022 has increased to 13.41 per 100,000 maternities (95% confidence interval (C 11.86-15.10). This compares to the rate of 11.66 per 100,000 maternities (95% CI 10.23-13.23) in 2019-21 (rate ratio (RR) 1.15, 95% CI 0.96-1.37, p=0.114); a non-significant increase was also seen when deaths due to COVID-19 were excluded. Compared to 2017-19, the last complete triennium (maternal mortality rate 8.79 per 100,000 maternities (95% CI 7.58-10.12), there was a statistically significant 53% increase (RR 1.53, 95% CI 1.26-1.85, p<0.001) in the maternal death rate in the UK in 2020-22. This increase remained statistically significant when deaths due to COVID-19 were excluded (RR 1.31, 95% CI 1.08 – 1.60, p=0.005).

The leading cause of death in the UK in 2020-22 during pregnancy or within 6 weeks of the end of pregnancy, was thrombosis and thromboembolism. COVID-19 was the second most common cause of maternal death followed by cardiac disease and psychiatric causes.

There remains and almost three-fold difference in maternal mortality rates amongst women from Black ethnic backgrounds, and an almost two-fold difference in rates amongst women from Asian ethnic backgrounds compared to White women. The apparent disparities in mortality rates of women from ethnic minority groups have decreased from 2019-21, but this should be considered in the context of an increase in the maternal mortality rate amongst White women. Women living in the most deprived areas have a maternal mortality rate more than twice as high as women living in the least deprived areas and this disparity is statistically unchanged from 2019-21.

More details can be found at https://www.npeu.ox.ac.uk/mbrrace-uk/data-brief after the embargo has lifted.

1.4 Data from national scrutiny of perinatal and maternity deaths

National Confidential Enquiries into maternal and perinatal deaths and maternal severe morbidities conducted by MBRRACE-UK continue to demonstrate improvements to care which may have made a difference to the outcome of care for women and/or their babies.

1.4.1 Perinatal Deaths

Reports from MBRRACE-UK on the rates of perinatal mortality in the UK continue to show disparities in the proportion of deaths of babies from different ethnic groups. The latest confidential enquiries

into perinatal deaths, published in December 2023, investigated the pregnancies of Black, Asian and White women in 2019, where the baby was stillborn or died within 28 days of birth (https://timms.le.ac.uk/mbrrace-uk-perinatal-mortality/confidential-enquiries/). The clinical care these women and their babies received was reviewed and compared with national guidelines for best practice. The evaluation of care also included an investigation into the quality of emotional and psychological help and support for women during pregnancy and when their baby died. These enquiries identified that improvements in care may have made a difference to the outcome of the baby for 42% of Black women, 26% of Asian women and 49% of White women. Improvements in care may have made a difference to the mother's outcome for 61% of Black women, 59% of Asian women and 69% of White women.

The report identified evidence of barriers to the care of vulnerable women including those requiring an interpreter and those with social complexities. The following national recommendations were made in the reports, noting that the number and scope of recommendations that the report is allowed to include is limited by the funder:

1. Develop national guidance and training for all health professionals to ensure accurate recording of women's and their partner's self-reported ethnicity, nationality and citizenship status, to support personalised care. **ACTION: RCOG, BAPM, National Institute for Health and Care Excellence (NICE),**
2. Provide maternity staff with guidance and training to ensure accurate identification and recording of language needs in order to support personalised care. This should include guidance about when it is appropriate to use healthcare professionals as interpreters. **ACTION: RCOG, BAPM, National Institute for Health and Care Excellence (NICE),**
3. Provide national support to help identify and overcome the barriers to local, equitable provision of interpretation services at all stages of perinatal care. This should including the resources to provide written information and individual parent follow-up letters in languages other than English. **ACTION: NHS England, NHS Wales, Scottish Government, and Northern Ireland Public Health Agency.**
4. Develop a UK-wide specification for identifying and recording the number and nature of social risk factors, updated throughout the perinatal care pathway, in order to offer appropriate enhanced support and referral**. ACTION: UK maternity data systems.**
5. Ensure maternity services deliver personalised care, which should include identifying and addressing the barriers to accessing specific aspects of care for each individual. **ACTION: Integrated Care Boards (England), Health Boards (Wales and Scotland), Local Commissioning Groups (Northern Ireland), research funders.**
6. Further develop and improve user guides for perinatal services, to empower women and families to make informed decisions about their care and that of their babies. **ACTION: Maternity and Neonatal Voice Partnerships, Maternity and Neonatal Safety Improvement Programme, NHS Wales, Scottish Government, Perinatal Network for Scotland, Northern Ireland Public Health Agency.**
7. Develop training and resources for all maternity and neonatal staff, so they can provide culturally and religiously sensitive care for all mothers and babies. **ACTION: NHS England, NHS Wales, Scottish Government, Perinatal Network for Scotland, Northern Ireland Public Health Agency and the RCOG, BAPM, RCPath, in conjunction with community and religious groups.**
8. Further develop existing PMRT guidance to ensure that all women's and parents' voices are actively sought, and their questions are addressed, as part of the local review carried out using the national Perinatal Mortality Review Tool. **ACTION: PMRT programme in collaboration with NHS England, NHS Wales, Scottish Government, Perinatal Network for Scotland, Northern Ireland Public Health Agency and the RCOG, RCM, BAPM, RCPath.**

9. Ensure that all relevant staff in Trusts and Health Boards have adequately resourced time in their work plans and contracted hours, and are supported to participate in local PMRT multidisciplinary review panels as internal and external members, so that these safety critical meetings are constituted and conducted appropriately and are never cancelled. **ACTION: NHS England, NHS Wales, Scottish Government, Perinatal Network for Scotland, and Northern Ireland Public Health Agency, RCOG, RCM, BAPM, RCPath.**

1.4.2 Maternal Deaths

The most recent confidential enquiry into maternal deaths, published in October 2023 (https://www.npeu.ox.ac.uk/mbrrace-uk/reports) investigated the care received by women who died from obstetric haemorrhage, amniotic fluid embolism, anaesthetic causes, infection, general medical and surgical disorders and epilepsy and stroke between 2019-21. It identified that improvements to care may have made a difference to the outcome for 98/190 (52%) of women who died. The report also included a confidential enquiry into the care of women with morbidity following repeat caesarean birth. It identified that improvements to care may have made a difference to the outcome for 23/32 (72%) of women who had a re-laparotomy after a repeat caesarean birth.

The report identified evidence of maternity systems under pressure and made the following national recommendations, noting that the number and scope of recommendations that the report is allowed to include is limited by the funder:

1. Update guidance to make certain that category 4 caesarean section lists are managed separately from more urgent caesarean sections to ensure these operations are not delayed to late in the day. **ACTION: National Institute for Health and Care Excellence (NICE)**
2. Update guidance on the use of coagulation tests in the context of obstetric haemorrhage including the timelines for availability and how to interpret these, noting that women should not be inappropriately denied clotting products based on a single measure of coagulation in the face of ongoing haemorrhage. **ACTION: National Institute for Health and Care Excellence (NICE), Royal College of Obstetricians and Gynaecologists, Royal College of Physicians, Obstetric Anaesthetists Association**
3. Review guidance on when to use balloon tamponade to control haemorrhage, how to insert the balloon and inflate it. Resources such as postpartum haemorrhage checklists should include when not to use balloon tamponade and when to abandon it and move on to a different haemostatic technique. **ACTION: National Institute for Health and Care Excellence (NICE), Royal College of Obstetricians and Gynaecologists,**
4. Review and revise the service specification for centres providing specialist services for managing abnormally invasive placentation to ensure that all specialist units can provide appropriate equipment, facilities and appropriately skilled personnel in an emergency situation occurring at any time of day or night. **ACTION: NHS England, Scottish, Welsh and Irish governments**
5. Clarify that review of the care of women who return to theatre may provide important safety learning but should not be perceived as a performance metric after caesarean birth, as re-operation may be the appropriate response to control internal haemorrhage. **ACTION: NHS England, Scottish, Welsh and Irish governments**
6. Ensure that pregnant and breastfeeding women are not excluded inappropriately from research, including new vaccine and treatment research, and ensure that messaging about benefits and risks of medication and vaccine use is clear and well informed with involvement of key opinion leaders and representatives of communities at risk from an early stage. Prepare a route to enable rapid dissemination of updated advice and data concerning new vaccines and treatments to both women and their clinicians in the future. **ACTION: Department of Health and Social Care and equivalents in Scotland, Wales and Ireland, UK**

Health Security Agency and equivalents in Scotland, Wales and Ireland, National Institute for Health Research and other funding agencies, Royal College of Obstetricians and Gynaecologists, Royal College of Midwives, Royal College of Physicians, Royal College of General Practitioners

7. Update guidance on ECMO for severe acute respiratory failure in adults to include specific information on referral and admission of pregnant and recently pregnant women with respiratory failure to ECMO services. **ACTION: National Institute for Health and Care Excellence (NICE)**
8. Ensure that staff working within maternal medicine networks are equipped with the skills to care for the complex and multiple medical, surgical, mental health and social care needs of the current maternity population. **ACTION: Maternal Medicine Networks**
9. Ensure that guidance on care for pregnant women with complex social factors is updated to include a role for networked maternal medical care and postnatal follow-up to ensure that it is tailored to women's individual needs and that resources in particular target vulnerable women with medical and mental health co-morbidities and social complexity. **ACTION: National Institute for Health and Care Excellence (NICE)**
10. Develop training resources concerning shared decision making and counselling regarding medication use in pregnancy and breastfeeding, including specific information on the benefits and risks of different medications and non-adherence. **ACTION: Royal College of Obstetricians and Gynaecologists, Royal College of Midwives, Royal College of Physicians, Royal College of General Practitioners, Medicines and Healthcare Products Regulatory Agency**

1.5 Examples of independent scrutiny of perinatal deaths and maternal deaths and its application at local, regional and national levels

The national independent scrutiny of maternal and perinatal deaths by MBRRACE-UK is described in section 1.4. The most recent report on the use of the Perinatal Mortality Review Tool, published in December 2023, (available at https://www.npeu.ox.ac.uk/pmrt/reports) provides data on independent scrutiny at a local level. The report presents findings relating to the 4,111 reviews using the Perinatal Mortality Review Tool started in the period March 2022 to February 2023 that were completed by 25th September 2023. The proportion of reviews involving an external independent member is now 45% (1847/4111), an increase from 34% in the previous annual report published in September 2022, (available at https://www.npeu.ox.ac.uk/pmrt/reports).

1.6 Evidence of adoption and quality of review

Evidence from the December 2023 report on the use of the Perinatal Mortality Review Tool (available at https://www.npeu.ox.ac.uk/pmrt/reports) shows the following:

- Local reviews using the Perinatal Mortality Review Tool were started for 97% of stillborn babies and those who died in the late second trimester (late miscarriages), and 95% of babies who died in the neonatal period (first four weeks after birth) in 2022. There has been an increase in these proportions since 2018, when the figures were 86% of stillborn babies and those who died in the late second trimester (late miscarriages), and 74% of babies who died in the neonatal period (first four weeks after birth)
- Overall in 2022-23, 96% of parents were told that a review of their baby's care would be taking place. 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 95%. A total of 2,174 reviews (53%) included comments, questions or concerns from parents; some provided multiple comments.

- There has been a steady improvement in the composition of the review teams which are now more multi-disciplinary 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 eight in 2022-23.
- Overall, in 95% of reviews at least one issue with care was identified (19 out of 20). In 20% (4 out of 20) reviews identified at least one issue with care that may have made a difference to the outcome for the baby.
- Previous reports have highlighted the need for action plans to be "strong", where strong actions are system level changes which remove the reliance on individuals to choose the correct action. These are actions that use standardisation and permanent physical or digital designs to eliminate human error and are sometimes referred to as 'forcing actions'. A random sample of 100 action plans was coded by strength. The proportion of strong and intermediate actions combined has increased and now represent 50% of all actions compared with 40% in the previous year's report.

These findings should be viewed alongside the observation from the most recent confidential enquiry into perinatal deaths, published in December 2023, (https://timms.le.ac.uk/mbrrace-uk-perinatal-mortality/confidential-enquiries/) that the hospital reviews, most of which were conducted using the Perinatal Mortality Review Tool, were more positive than the conclusions reached by the confidential enquiry panels.

Dec 2023