Maternal, Newborn and
Infant Clinical Outcome
Review Programme

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

# MBRRACE-UK
# Perinatal Confidential Enquiry

## A comparison of the care of Black and White women who have experienced a stillbirth or neonatal death

## State of the Nation Report

December 2023

HQIP
Healthcare Quality Improvement Partnership
UNIVERSITY OF LEICESTER
UNIVERSITY OF BIRMINGHAM
The Newcastle upon Tyne Hospitals NHS Foundation Trust
TIMMS
Sands Stillbirth & neonatal death charity
Chelsea and Westminster Hospital NHS Foundation Trust
UNIVERSITY OF OXFORD
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## Funding

The Maternal, Newborn and Infant Clinical Outcome Review Programme, delivered by MBRRACE-UK, is commissioned by the Healthcare Quality Improvement Partnership (HQIP) as part of the National Clinical Audit and Patient Outcomes Programme (NCAPOP). 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. The Clinical Outcome Review Programmes, which encompass confidential enquiries, are designed to help assess the quality of healthcare, and stimulate improvement in safety and effectiveness by systematically enabling clinicians, managers, and policy makers to learn from adverse events and other relevant data. HQIP holds the contract to commission, manage, and develop the National Clinical Audit and Patient Outcomes Programme (NCAPOP), comprising around 40 projects covering care provided to people with a wide range of medical, surgical and mental health conditions. The programme is funded by NHS England, the Welsh Government and, with some individual projects, other devolved administrations and Crown Dependencies.

More details can be found on the HQIP website.

## Stakeholder involvement

Organisations representing parents and families are involved in the MBRRACE-UK programme as part of the 'Third Sector' stakeholder group, identifying possible areas for future research and helping to communicate key findings and messages from the programme to parents, families, the public and policy makers, including through the development of lay summary reports. A full list of organisations can be found in the acknowledgements.

This enquiry, including the State of the Nation Report, was developed in consultation with our Topic Expert Group, multidisciplinary panel members and 'Third Sector' stakeholder group.

## Cohort

Deaths reviewed are from England, Wales, Scotland and Northern Ireland, for the period 1 July 2019 to 31 December 2019 inclusive.

## Version history

| Version | Details of changes | Release date |
|---|---|---|
| 1.0. | First published. | 14/12/2023 |
| 1.1. | Section 5.3 was revised in order to clarify current recommendations on vitamin D. | 11/01/2024 |

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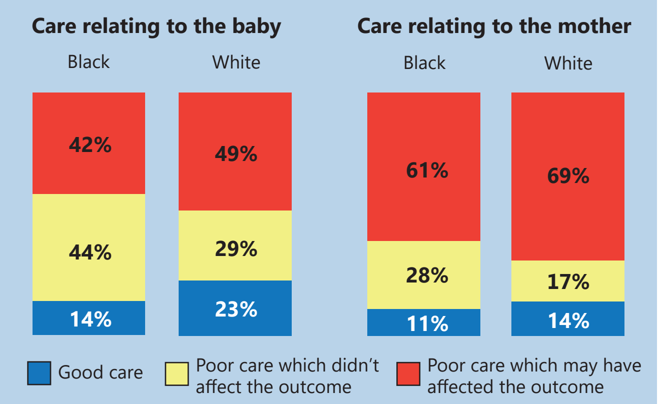
# Comparing the care of Black and White women whose babies died

Baby deaths in 71 pregnancies reviewed → 36 Black women / 35 White women → Medical notes reviewed by clinical experts



| | |
|---|---|
| Women's ethnicity, nationality and citizenship status was not always recorded well. | All women should be asked about their ethnicity, nationality and citizenship status, to help provide care that is tailored to their specific needs. |
| When a woman's first language wasn't English and she needed an interpreter, this wasn't always provided. | Women should be offered information about maternity care in different ways. An interpreter should be offered at each appointment, if the woman needs it to understand the information she is given or to talk to her doctor or midwife. |
| Some women faced challenges in their personal lives which were not always recognised or taken into account when planning their care. These challenges were more common for White women. | Information about women's personal and social risk factors should be written in the notes, and updated throughout the pregnancy, so that extra support can be provided if it is needed. |
| Some Black women found it difficult to get certain types of care or advice, even if it was offered to them. | Maternity care should be personalised to the needs of each woman. Women should be helped to overcome any problems that make it hard for them to get the care they need. |
| Blood tests to check for gestational diabetes were not offered to 1 in 3 Black women. Almost all White women who should have been tested were offered a test. | All women with risk factors for gestational diabetes, which includes all Black women, should be offered a test between 24 and 28 weeks of pregnancy. |
| All the Black women should have been offered a high dose of Vitamin D to take during their pregnancy, but none of them were. | All women should be offered Vitamin D to take during pregnancy, and women with darker skin or a BMI over 30 may be offered a higher dose. |
| Bereavement care was good for most parents. | Family-centred bereavement care, in line with the National Bereavement Care Pathway, should be offered to all parents. |
| Almost all baby deaths were reviewed using the Perinatal Mortality Review Tool. The hospital reviews were more positive than the conclusions reached by the confidential enquiry panels. | Hospitals should make sure that reviews are carried out by enough people from the right specialties. At least one of these people should be from another hospital. |
| When a review did take place, most parents didn't have any questions or talk about their experience, especially if they didn't speak English. | As part of the review process, parents should be supported to ask questions and talk about their experience, to ensure they receive answers about why their baby died. |
| Most parents had a follow-up meeting with their consultant to review their care, but not all had a letter summarising what they talked about. Black parents were less likely to receive a letter than White parents. | All parents should have a follow-up meeting (jointly with their obstetrician and neonatal doctor, if appropriate) to review their and their baby's care, and a clear and personalised written summary should be given to the parents. |

## Recommendations and supporting evidence

| Recommendation | Target audience | Supporting evidence |
|---|---|---|
| 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. | RCOG, BAPM, National Institute for Health and Care Excellence (NICE). | There was frequently inaccurate and inconsistent recording of citizenship and ethnicity within the maternity records, that may have impacted on the ability to undertake assessment of needs and personalised care planning. For 18 (50%) Black women and 4 (11%) White women citizenship status was not recorded.<br>Women's ethnic group and origins were described in varying ways throughout their records, from generic terms to detailed country of birth, and with varying accuracy and consistency, reflecting a lack of awareness or understanding of the importance of women's backgrounds. There were also examples of the conflation of ethnicity with nationality, country of birth, citizenship status, and religion. **(Section 4.4)** |
| 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. | RCOG, BAPM, National Institute for Health and Care Excellence (NICE). | National guidance recommends that healthcare professionals should help support women to access maternity services through various methods to communicate information about antenatal care, ensuring that reliable interpretation services are available when needed. Whilst language difficulties were not the predominant vulnerability within the White or Black group, English was not the first language for 12 (33%) Black women (all Black African) and 4 (11%) White women (all Eastern European).<br>Case reviews identified major or significant language issues, which were probably or almost certainly relevant to the outcome, for three Black and two White women. Whilst interpretation services were recorded as being required for four Black and two White (Eastern European) women, they were not consistently provided. For example, one Black woman had no interpreter provision and notably ambiguous documentation regarding her language ability. Possible language needs were not identified for an additional two Black women. In several cases healthcare professionals were used as interpreters.<br>In addition to providing information in an appropriate format and language, an assessment should be made of the woman's understanding. There was no evidence that this had been undertaken for any of the women where English was not their first language. **(Section 4.4)** |
| 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 include the resources to provide written information and individual parent follow-up letters in languages other than English. | NHS England, NHS Wales, Scottish Government and Northern Ireland Public Health Agency. | There were no examples of use of interpretation services throughout the women's care pathway. **(Section 4.4)**<br>The majority of parents either explicitly indicated they had no questions or concerns to raise or they never communicated any questions or concerns to the hospital. Parents with an identified language barrier, regardless of ethnicity, were all in the latter group. **(Section 6.4)**<br>The number of poor quality reviews was slightly greater for the babies of White than Black ethnicity, although the range of elements identified as poor quality was not notably different. The lack of, or poor quality of, interpretation services was identified as an issue with care together with action plans relating to providing interpretation services and written material in other languages for only half of the women with an identified language barrier. **(Section 6.5)** |
| 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. | UK maternity data systems. | Social risk factors were the predominant vulnerability within White women, who were more likely to experience multiple disadvantage, mental health issues and social services involvement. There were also more White women who were not referred for additional support, most commonly regarding substance misuse or safeguarding concerns. It was noted that social risk factors were not recorded systematically within the maternity records of both groups and therefore there may have been limited identification and referral. Where women had multiple social risk factors there was a lack of multi-disciplinary |

| Recommendation | Target audience | Supporting evidence |
|---|---|---|
| | | team working and a failure to consider the woman's care from a holistic perspective. **(Section 4.5)** |
| 5. Ensure maternity services deliver personalised care, which should include identifying and addressing the barriers to accessing specific aspects of care for each individual. | Integrated Care Boards (England), Health Boards (Wales and Scotland), Local Commissioning Groups (Northern Ireland), research funders. | Black women were more likely to experience barriers to accessing specific aspects of care that were offered. **(Table 10)** |
| 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. | Maternity and Neonatal Voice Partnerships, Maternity and Neonatal Safety Improvement Programme, NHS Wales, Scottish Government, Perinatal Network for Scotland, Northern Ireland Public Health Agency. | Access to routine maternity care was explored using timing of booking, acceptance of routine screening and the management of non-attendance at appointments. While the majority of non-attendances (DNAs) were followed up, there were also examples of this not being explored in any detail and a lack of personalised care being provided. Therefore, missed opportunities to improve access to care were identified as suboptimal care which was possibly relevant to the outcome. **(Section 4.6, Vignette 6)**<br>Black women were more likely to experience barriers to accessing specific aspects of care that were offered. **(Table 10)** |
| 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. | 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. | Access to routine maternity care was explored using timing of booking, acceptance of routine screening and the management of non-attendance at appointments. While the majority of non-attendances (DNAs) were followed up, there were also examples of this not being explored in any detail and a lack of personalised care being provided. Therefore, missed opportunities to improve access to care were identified as suboptimal care which was possibly relevant to the outcome. **(Section 4.6, Vignette 6)**<br>The majority of parents either explicitly indicated they had no questions or concerns to raise or they never communicated any questions or concerns to the hospital. Parents with an identified language barrier, regardless of ethnicity, were all in the latter group. **(Section 6.4)** |
| 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. | 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. | According to the PMRT reports reviewed by the enquiry, where a PMRT review had been undertaken, all parents had been informed that a local review of care would take place. They were also all invited to communicate any questions or concerns they had about their care and that of their baby. A small number of parents took this opportunity to express their gratitude for the care they had received. The majority of parents either explicitly indicated they had no questions or concerns to raise or they never communicated any questions or concerns to the hospital. Parents with an identified language barrier, regardless of ethnicity, were all in the latter group. About a third of parents of both groups of babies asked questions and/or expressed concerns about their care. **(Section 6.4)** |
| 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. | NHS England, NHS Wales, Scottish Government, Perinatal Network for Scotland, Northern Ireland Public Health Agency, RCOG, RCM, BAPM, RCPath. | Eleven out of 34 reviews of the care of babies of Black ethnicity and seven out of 32 reviews of the babies of White ethnicity were carried out by a review group which included less than five members; this is too few to constitute a multidisciplinary group. The median number of members of the review panel was six for both groups of babies. External members were present for eight of the reviews of babies of Black ethnicity (with two external members for four reviews) and five of the reviews of babies of White ethnicity. **(Section 6.6)** |

# MBRRACE-UK Perinatal Confidential Enquiry

## A comparison of the care of Black and White mothers who have experienced a stillbirth or neonatal death

### State of the Nation Report

# 1. Introduction

## 1.1. Report overview

This report presents the findings of the fifth perinatal confidential enquiry carried out as part of the MBRRACE-UK programme of work, and investigates any differences in the quality of care provision for mothers of Black and White ethnicity whose pregnancy ends in stillbirth or neonatal death. This topic was selected by the Maternal, Newborn and Infant Clinical Outcome Review Programme (MNI-CORP) Independent Advisory Group following a call for topic proposals. The enquiry assessed care provision along the whole care pathway, to identify areas of care requiring improvement.

Additional supporting materials to accompany this report include:

- a set of data tables;
- full details of the MBRRACE-UK confidential enquiry methodology;
- enquiry evaluation forms and checklists.

## 1.2. Terminology

In this report we use the terms 'women' and 'mothers'. However, we acknowledge that not all people who access perinatal services identify as women and mothers, and that our recommendations apply to all people who are pregnant or have given birth. Likewise, use of the word 'parents' includes anyone who has the main responsibility of caring for a baby.

# 2. Background

## 2.1. Context for the enquiry

Since the inception of MBRRACE-UK in 2013 perinatal surveillance reports have shown very high rates of stillbirth and neonatal death for the Black population compared with the White population. When this enquiry was being planned, the MBRRACE-UK perinatal surveillance report for UK perinatal deaths for births from January to December 2019 showed that babies of Black or Black British ethnicity were at 124% increased risk of stillbirth and 43% increased risk of neonatal mortality compared with babies of White ethnicity. More recent data shows that this disparity continues. This confidential enquiry provides an opportunity to address this major issue by providing insight into the reasons for these marked differences in risk using this methodology to compare the quality of care provision for the Black population with that provided for the White population.

## 2.2. Aims

The aims of this enquiry were to address the following questions:

- To what extent are applicable guidelines followed in the care of Black women who experience a stillbirth or neonatal death?
- Would improvements in care have resulted in the stillbirth or neonatal death being prevented?

- What lessons can be learned to help prevent stillbirth and neonatal death for Black women in the future?
- To what extent were markers of good quality care present
- Are the findings from the enquiry the same or different for Black and White women who experience a stillbirth or neonatal death?

To meet these aims the focus of this enquiry was to investigate any differences between the care provision for Black and White women, in order to investigate the role of ethnicity in the increased rates of stillbirth and neonatal death for the Black population. Previous enquiries have reported quality of care issues along the care pathway that may be of relevance to one or both ethnic groups. These will primarily be reported only where a difference is found between Black and White mothers and babies.

## 2.3. The confidential enquiry process

As detailed in previous MBRRACE-UK reports, a confidential enquiry is a process of systematic, multidisciplinary, anonymous case review where a consensus opinion is reached about the quality of care provision for all cases undergoing review. Our previous confidential enquiries have demonstrated the ability of this method to make inferences about quality of care provision. However, it is important to state the potential limitations of this method. A confidential enquiry cannot identify other important differences in care that may have occurred but were not documented, or not sufficiently detailed in the clinical notes available for confidential enquiry panel review. These could include biased attitudes of staff or any behaviours that may influence non-verbal communication, elements that can only be identified by collection of data directly from mothers and families about their experiences. A confidential enquiry also does not have access to information about specific organisational structure, practice and culture. The confidential enquiry process is therefore also limited in its ability to identify examples of structural or systemic racism; the process cannot always identify the circumstances which led to events.

The basic premise of any confidential enquiry is "if it is not written in the notes then it did not happen", as is the case for legal cases. Clearly this then relies on accuracy and completeness of note taking throughout the whole care pathway in both handwritten and electronic notes as well as reports and letters. This method does not provide an opportunity for individual parent feedback due to the confidential nature of these enquiries. In this enquiry where we are trying to determine not only whether standards and guidance were adhered to but also issues around accessibility, engagement and individual interactions with women during their care, it must be recognised that this can be very difficult to determine from clinical notes, letters and reports alone. This report is therefore limited to those issues where adequate information has been provided in order to allow more nuanced findings to emerge.

In order to ensure ethnic and cultural understanding and sensitivity within panel reviews each review panel included health professionals from Asian, Black and White backgrounds.

As in previous enquiries the focus was on both good and poor quality care comparing care provision for Black and White women and their babies. The standard MNI-CORP criteria, adopted by all enquiries in the programme, were used to summarise the holistic assessment of the overall quality of care separately for each mother in terms of her psychological and physical well-being and future fertility, and baby in terms of any factors that may have affected the outcome (Box 1).

**Box 1: Overall grading of care**

- Good care, no improvements identified;
- Improvements in care identified which would have made no difference to outcome; [note 1]
- Improvements in care identified which may have made a difference to outcome. [note 1]

Note 1: Improvements in care should be interpreted to include adherence to guidelines and standards, where these exist and have not been followed, as well as other improvements which would normally be considered part of good care where no formal guidelines exist.

In addition to the overall assessments, each aspect of care along each point of the care pathway was evaluated with respect to the quality of care provision as shown in Box 2. For each assessment of the quality of care provision review panels also record whether it had any relevance to the outcome for either the baby or the mother as applicable.

**Box 2: Grading of care at each point of the care pathway**

- None: good quality care identified;
- Minor: minor issues with the quality of care identified;
- Significant: significant issues with the quality of care identified;
- Major: major issues with the quality of care identified.

Full details of the methods used for this enquiry, including the development of panel guidance documents, checklists, selection of multidisciplinary panel members and panel meetings can be found as part of the online version of this report.

### 2.4. Eligible pregnancies

Women and babies eligible for inclusion in this enquiry were defined as:

- Singleton pregnancy;
- Mother's ethnicity, as reported to MBRRACE-UK, was Black (Black African, Black Caribbean, or Other Black) or White. This may not necessarily coincide with the woman's self-reported ethnicity;
- The outcome was a stillbirth or neonatal death;
- Gestational age at birth was 24 completed weeks or more; and
- The baby was born between 1 July 2019 and 31 December 2019.

Pregnancies which involved terminations of pregnancy were excluded. The sample was selected from the MBRRACE-UK perinatal mortality surveillance data for 2019. A total of 50 mother and baby pairs were initially selected for each ethnic group. Cases were then submitted for review by confidential enquiry until saturation of themes was achieved and no new lessons for future care were emerging. In total, 35 White and 36 Black pregnancies were reviewed; one mother whose ethnicity was reported to MBRRACE-UK as Asian was reclassified as Black on detailed review of the clinical notes.

### 2.5. Representativeness of the sample

For each ethnic group, the representativeness of the random samples of pregnancies reviewed for the enquiry were compared with the remaining eligible pregnancies (96 Black, 1,102 White), with respect to their maternal socio-demographic, behavioural and care characteristics, as well as the baby characteristics (see characteristics tables). Using a random sample allows for the generation of results that are representative of all relevant Black and White pregnancies thus allowing for both the quantitative analysis of the data and a qualitative investigation of how care was provided to women and their babies.

There were no statistically significant differences found between the reviewed and non-reviewed pregnancies in terms of maternal socio-demographic, delivery or care characteristics for either the Black or White groups (see the characteristics tables for full details). However, in terms of the baby characteristics, for the Black group there were significantly more male babies in those reviewed by the enquiry. Given the focus of the study on the care provision to mothers and their babies, this difference in the sex of the babies was not felt to have had an impact on the findings. The reviewed and non-reviewed White groups had no significant differences in terms of baby characteristics. We therefore concluded that the results from this enquiry are likely to be representative of all stillbirths and neonatal deaths to mothers who are Black and White, where the baby was born in the UK between 1 July 2019 and 31 December 2019.

### 2.6. Structure of the report

An overall summary of the care provision for mothers and babies will be presented, followed by summary findings along the care pathway. Analysis of the data from the enquiry panels identified two key areas where differences were noted between the quality of care provided for Black and White mothers and babies. These are vulnerabilities of the women and reviews of baby deaths. Separate sections are therefore presented for: vulnerabilities identified in Black and White women; issues along the care pathway; and review of baby deaths.

## 3. Overall findings

### 3.1. Introduction

The overall findings of this enquiry are based on the consensus opinion of panel members concerning the quality of care provided for the 36 Black and 35 White mothers and their babies. Previous confidential enquiries have identified many issues with the quality of care provided along the whole care pathway and recommendations have been made to address these. This enquiry was developed to try and identify any differences in the quality of care provided to women of Black ethnicity compared with their White counterparts and will form the main focus of this report. Recommendations will therefore be targeted at trying to ensure equity for the quality of care provision for both Black and White mothers and their babies.

### 3.2. Key findings

- Improvements in care were identified which may have made a difference to the outcome of the baby for 42% of Black women and 49% of White women.
- Improvements in care were identified which may have made a difference to the outcome for the mother in 61% of

Black women and 69% of White women.

- Major or significant issues were found with antenatal care provision for 83% of Black women compared with 69% of White women.
- 33% of Black women and 54% of White women had major or significant care issues during postnatal and bereavement care.
- 67% of Black mothers and babies and 46% of White mothers and babies had major or significant issues identified with respect to pathology.
- 75% of Black parents and 66% of White parents had major or significant issues identified at follow-up or during review of their care and that of their babies.

## 3.3. Grading of quality of care

A summary of the consensus findings of the panel reviews is provided in Table 1, indicating the quality of care provision for the outcome of both the babies and the mother across all aspects of the care pathway by ethnic group.

**Table 1: Summary of holistic grading of quality of care for babies and mothers**

| Overall quality of care for Black babies and mothers | Babies N=36 | Babies % | Mothers N=36 | Mothers % |
|---|---|---|---|---|
| Good care; no improvements identified | 5 | 14 | 4 | 11 |
| Improvements in care identified which would have made no difference to outcome [note 1] | 16 | 44 | 10 | 28 |
| Improvements in care identified which may have made a difference to outcome [note 1] | 15 | 42 | 22 | 61 |
| Overall quality of care for White babies and mothers | Babies N=35 | Babies % | Mothers N=35 | Mothers % |
| Good care; no improvements identified | 8 | 23 | 5 | 14 |
| Improvements in care identified which would have made no difference to outcome [note 1] | 10 | 29 | 6 | 17 |
| Improvements in care identified which may have made a difference to outcome [note 1] | 17 | 49 | 24 | 69 |

Note 1: From the point of view of the baby, the panels broadly interpreted 'outcome' to represent whether the care provision may have contributed to the death. From the mother's perspective, 'outcome' was interpreted as her physical and psychological wellbeing and full consideration of her future fertility.

Overall, in terms of the outcome for the baby, the panel consensus was that in 42% of Black and 49% of White mothers and babies reviewed, improvements in care were identified which may have made a difference to the outcome for the baby. In terms of the mother's physical and psychological outcome and/or future fertility, the consensus of the panels was that improvements in care may have made a difference in around 62% of Black mothers and 69% of White mothers. Good care throughout the care pathway was noted for fewer Black babies: 14% compared with 23% for White babies, although similar levels of good care were noted in terms of outcomes for both Black and White mothers (11% and 14% respectively).

Our previous confidential enquiries have shown that reducing such complex cases to a single number in order to describe the quality of care provision for the mother or the baby is limited, and does not provide a complete picture of the entire pathway of care provision. The basis of the allocation of the grade of quality of care may be based on one aspect alone, so an improvement in care might be identified for a case which had excellent care throughout the whole of the care pathway except for one element. Alternatively, a case may have had poor care throughout the care pathway affecting both the ultimate outcome for the baby and the future health and wellbeing of the mother. In contrast, a case may have had several aspects of care quality that did not affect the ultimate outcome for the baby, but resulted in care that may have made a difference in terms of the mother's experience and future health and fertility.

Tables 2 and 3 provide information about the poorest grading of quality of care affecting the outcome for the baby and mother for each ethnic group at each relevant point along the care pathway. There is a vast array of guidance and standards aimed at antenatal care and high proportions of both Black and White pregnancies were determined by the panels to have major or significant issues during this period: 83% for Black pregnancies compared with 69% of White pregnancies. Major or significant care issues were identified for around half of both Black and White pregnancies and babies in terms of care provision during labour and birth, resuscitation and neonatal care (but numbers were very small for the latter categories due to the low numbers of neonatal deaths in each group). During postnatal and bereavement care one third (33%) of Black women received care graded with major or significant issues compared with over half (54%) of the White women. The greatest difference in the standard of care provision between the two groups of women was for pathology which encompasses placental histology, the consenting process for post-mortem, provision of clinical information and the quality of reporting with 67% of Black mothers and babies being graded as having major or significant issues compared with under half (45%) of White mothers and babies. High proportions of both Black and White families had major or significant issues identified at follow-up or review of their care and that of their babies: 75% and 66%, respectively.

**Table 2: Poorest grading of quality of care issues affecting the outcome for the baby: point on the care pathway and mother's ethnicity**

| Quality of care issues: Black | Antenatal N | Antenatal % | Labour & Birth N | Labour & Birth % | Resuscitation N [note 1] | Resuscitation % | Neonatal N [note 1] | Neonatal % |
|---|---|---|---|---|---|---|---|---|
| None | 6 | 17 | 18 | 50 | 1 | 17 | 3 | 50 |
| Minor | 0 | 0 | 1 | 3 | 2 | 33 | 0 | 0 |
| Significant | 11 | 31 | 7 | 19 | 2 | 33 | 1 | 17 |
| Major | 19 | 53 | 10 | 28 | 1 | 17 | 2 | 33 |
| All | 36 | 100 | 36 | 100 | 6 | 100 | 6 | 100 |
| Quality of care issues: White | Antenatal N | Antenatal % | Labour & Birth N | Labour & Birth % | Resuscitation N [note 1] | Resuscitation % | Neonatal N [note 1] | Neonatal % |
| None | 8 | 23 | 15 | 43 | 4 | 50 | 4 | 50 |
| Minor | 3 | 9 | 2 | 6 | 1 | 13 | 0 | 0 |
| Significant | 9 | 26 | 8 | 23 | 1 | 13 | 1 | 13 |
| Major | 15 | 43 | 10 | 29 | 2 | 25 | 3 | 38 |
| All | 35 | 100 | 35 | 100 | 8 | 100 | 8 | 100 |

Note 1: Denominator reflects the number of babies who received care at this point in the care pathway

**Table 3: Poorest grading of quality of care issues affecting the outcome for the mother: point on the care pathway and mother's ethnicity**

| Quality of care issues: Black | Postnatal & bereavement N | Postnatal & bereavement % | Pathology N | Pathology % | Follow-up & review N [note 1] | Follow-up & review % |
|---|---|---|---|---|---|---|
| None | 20 | 56 | 10 | 28 | 9 | 25 |
| Minor | 4 | 11 | 2 | 6 | 0 | 0 |
| Significant | 6 | 17 | 9 | 25 | 9 | 25 |
| Major | 6 | 17 | 15 | 42 | 18 | 50 |
| All | 36 | 100 | 36 | 100 | 36 | 100 |
| Quality of care issues: White | Postnatal & bereavement N | Postnatal & bereavement % | Pathology N | Pathology % | Follow-up & review N [note 1] | Follow-up & review % |
| None | 16 | 46 | 17 | 49 | 11 | 31 |
| Minor | 0 | 0 | 2 | 6 | 1 | 3 |
| Significant | 10 | 29 | 6 | 17 | 6 | 17 |
| Major | 9 | 26 | 10 | 29 | 17 | 49 |
| All | 35 | 100 | 35 | 100 | 35 | 100 |

One further summary measure focussed on the points of the care pathway present in all pregnancies: antenatal care, labour and birth, postnatal and bereavement care, pathology, and follow-up and review. For each point on the care pathway where major or significant issues were identified one point was allocated. Each mother and baby pair could therefore have a score between 0 and 5, where 0 represents good quality care with no issues at any point and 5 represents major or significant care issues at all points of the care pathway. Findings were very similar between the two groups, with around 40% scoring four or more (42% Black, 40% White) and one-third scoring two or less (33% Black, 34% White).

**Table 4: Major or significant care issues identified along the care pathway**

| Total score [note 1] | Black N=36 | Black % | White N=35 | White % |
|---|---|---|---|---|
| 0 – No major or suboptimal care issues at any point on the care pathway | 1 | 3 | 4 | 11 |
| 1 | 4 | 11 | 3 | 9 |
| 2 | 7 | 19 | 5 | 14 |
| 3 | 9 | 25 | 9 | 26 |
| 4 | 10 | 28 | 10 | 29 |
| 5 – Major or suboptimal care issues at all points on the care pathway | 5 | 14 | 4 | 11 |

Note 1: Score represents major or significant care issues identified at the stages of the care pathway present in all pregnancies.

### 3.4. Overall summary of quality of care

Improvements in care which may have made a difference to the outcome for the baby or the mother were similar for both Black and White mothers and babies. Along the care pathway, major or significant issues with care were more common for Black mothers and babies compared with White mothers and babies for antenatal care, pathology and at follow-up and review, but less common during postnatal and bereavement care.

## 4. Vulnerabilities identified in Black and White women

### 4.1. Introduction

The MBRRACE-UK perinatal confidential enquiry reviewed the care of 36 Black women (22 Black African, 11 Black Caribbean and three Black Other women) and 35 White women (including four Eastern European women). As identified in previous reports and enquiries, it was noted that women at severe disadvantage and vulnerabilities appear to be over-represented.

### 4.2. Key findings

- There was variation and inconsistency in the recording of ethnicity, nationality and citizenship status
- Identifying and responding to language needs are inadequate across all ethnic groups
- Inconsistent use of independent interpretation services was noted for all women who needed it, with inappropriate use of family members and healthcare professionals
- Access to care and engagement (late booking, acceptance of routine combined screening and follow up of non-attendance at appointments) was similar between Black and White women
- Compared with White women, fewer Black women had evidence of routine mental health questions being asked. Few women in either the Black or White groups were asked routine mental health questions in the postnatal period.
- Black women were more likely to experience barriers to accessing specific aspects of care or advice that were offered which resulted in some women not taking prescribed medicines, taking their own discharge against advice, and not attending specialist appointments.
- Many complex social risk factors were not recorded systematically. However, they were more commonly identified in White women.
- There was a lack of personalised care which was both kind and compassionate

### 4.3. Women with complex social risk factors

We adopted the approach used by other researchers exploring the role of social risk factors and engagement with maternity services.

Information regarding social risk factors was identified by healthcare professionals’ documentation in the case notes such as tick box checklists, appointment summaries or letters. This information usually originated from women, often at the initial booking into maternity care as part of a routine assessment, but may also have been added to or amended at later points. Information regarding ethnicity, nationality and citizenship was extracted from the notes, where recorded. Complex social risk factors were defined using the Revolving Doors Agency and Birth Companions criteria (see Box 3 below). These were deemed appropriately addressed where they were identified and discussed or the woman was referred to support services by maternity care providers.

**Box 3: Complex social risk factors**

- Domestic violence or abuse
- Substance misuse
- Mental health issues
- Criminal justice involvement
- Homelessness
- Young age (under 20 years)
- Physical disability
- Learning difficulty
- Significant financial need
- Recent migrant (less than 1 year in UK)
- Unable to speak or understand English
- Social services involvement

Source: Revolving Doors Agency and Birth Companions, "Making Better Births a reality for women with multiple disadvantages".

Late booking was defined according to the NHS key performance indicator recommending that antenatal assessment should occur before 13 weeks, or by the twelfth week for woman giving birth in Scotland. Whether or not women received the minimum number of recommended antenatal visits was determined by comparing the number of routine visits to the schedule recommended by NICE (ten for nulliparous and seven for multiparous women), taking into account gestational age at birth and death. Screening was defined as routine NICE recommended blood tests and ultrasound scans for both maternal and fetal conditions. Routine mental health assessment should be undertaken in both the antenatal and postnatal periods as recommended by NICE.

The enquiry panels identified three prominent types of vulnerabilities: language, complex social needs and engagement. These were present in both of the groups, however, there was variation in the prevalence of these three themes across the ethnic groups.

## 4.4. Identification and recording of citizenship, language needs and the provision of interpretation services

The panels noted that there was frequently inaccurate and inconsistent recording of citizenship and ethnicity within the maternity records, that may have impacted on the ability to undertake assessment of needs and personalised care planning. For 18 (50%) Black women and 4 (11%) White women citizenship status was not recorded

**Table 5: Citizenship status**

| Citizenship status | Black women N=36 | White women N=35 |
|---|---:|---:|
| UK Citizen | 13 | 30 |
| EU Citizen | 1 | 1 |
| Non-EU Citizen | 2 | 0 |
| Indefinite leave to remain | 1 | 0 |
| Refugee | 1 | 0 |
| Not documented | 18 | 4 |

Women's ethnic group and origins were described in varying ways throughout their records, from generic terms to detailed country of birth, and with varying accuracy and consistency, reflecting a lack of awareness or understanding of the importance of women's backgrounds. There were also examples of the conflation of ethnicity with nationality, country of birth, citizenship status, and religion.

National guidance recommends that healthcare professionals should help support women to access maternity services through various methods to communicate information about antenatal care, ensuring that reliable interpretation services are available when needed. Whilst language difficulties were not the predominant vulnerability within the White or Black group, English was not the first language for 12 (33%) Black women (all Black African) and 4 (11%) White women (all Eastern European).

Case reviews identified major or significant language issues, which were probably or almost certainly relevant to the outcome, for three Black and two White women. Whilst interpretation services were recorded as being required for four Black and two White (Eastern European) women, they were not consistently provided. For example, one Black woman had no interpreter provision and notably ambiguous documentation regarding her language ability. Possible language needs were not identified for an additional two Black women that are not represented within Table 7. In several cases healthcare professionals were used as interpreters. This is not advised in primary care settings where guidance states that they should not take on the role of an interpreter, other than to assist patients in making appointments, to assess language needs, or where immediate and necessary treatment is required, unless this is part of their defined job role and they are qualified to do so. There is no equivalent guidance for secondary care.

### Table 6: Identification of language needs and interpreter provision

| Language needs | Black women N=36 | White women N=35 |
|---|---|---|
| First language not English (all) | 12 | 4 |
| First language not English, and difficulty in reading or speaking English | 4 | 2 |
| First language not English, and required an interpreter [note 1] | 4 | 2 |
| Trained interpreter or language line used at any point in the care pathway | 3 | 2 |
| Antenatal | 3 | 2 |
| Birth plan | 0 | 2 |
| Intrapartum | 2 | 1 |
| Neonatal [note 2] | 1 | 0 |
| Postnatal | 3 | 1 |
| Follow-up | 2 | 1 |
| Appropriate interpreter provision at each contact with services | 0 | 0 |

Note 1: Four Black African women required an interpreter. Two White Eastern European women required an interpreter.
Note 2: Where an interpreter was required this was provided for one out of three Black babies and none out of two White babies during neonatal care.

Where language is a problem in discussing health matters, NHS England, NHS Scotland and Northern Ireland Health & Social Care guidance stipulate that a professional interpreter should always be offered, rather than using family or friends to interpret. There is currently no equivalent guidance for Wales. Detailed guidance is also given in the Migrant Health Guide. Within the maternity setting NICE guidance also provides recommendations regarding the provision of interpretation services to facilitate information provision and communication between healthcare professionals and women. The Royal College of Midwives (RCM) has also produced guidance on caring for vulnerable migrant women and women experiencing severe and multiple disadvantage, although the deaths reviewed by the enquiry predate these particular pieces of guidance.

### Vignette 1: Inconsistent use of interpretation services

A Black African woman with refugee status was correctly assessed as requiring interpretation services when she booked her first pregnancy. She had seven antenatal contacts. At five of these contacts professional interpretation services were present. One appointment was rearranged due to the lack of an interpreter, and there was one contact where no interpretation services were utilised. Following the confirmation of an intrauterine fetal death the use of a professional interpreter became more inconsistent. There were occasions when male family members were used, and examples of the obstetric team waiting for the arrival of a face to face interpreter rather than using other types of interpretation services in the interim period.

In addition to providing information in an appropriate format and language, an assessment should be made of the woman's understanding. There was no evidence that this had been undertaken for any of the women where English was not their first language, however it was recognised by the panel that assessments are not routinely recorded.

### Vignette 2: Poor assessment of language needs

A non-English speaking Black African woman in her first pregnancy, was found by her neighbours in her third trimester, distressed and experiencing shortness of breath whilst away from home. She attended A&E, following which she was transferred to maternity triage. Despite documentation of elevated blood pressure, pre-eclampsia was not excluded and a cardiotocograph (CTG) was not undertaken as part of the obstetric review. She presented again 6 days later, with an abruption and intrauterine death. Enquiry panel members noted that she had not been provided with interpretation services throughout her pregnancy, with family members and friends providing interpretation during consultations. Although a leaflet regarding reduced fetal movements had been provided, it is not certain whether the woman was able to understand the information. The panel identified that this was probably or almost certainly relevant to the outcome.

There were no examples of use of interpretation services throughout the women's care pathway. However, there were areas where good care was noted.

**Vignette 3: Good use of interpretation services along the care pathway**

A White teenage woman from Eastern Europe booked her second pregnancy late into her second trimester, and was correctly assessed as requiring interpretation services for every contact. The anomaly scan identified multiple abnormalities and an emergency health care plan was formulated for birth. There were multiple antenatal contacts, with a mixture of face-to-face and telephone interpreters and the use of online translation services. There was evidence that a named translator had been present for five of these appointments, including the bereavement appointment, which provided good continuity for a vulnerable woman.

Within clinical practice accessing good quality independent interpretation services can be challenging with associated cost pressures, however there was consensus within the panels that inadequate resources were a contributory factor impacting upon outcomes within both groups.

## 4.5. Inconsistent identification of social risk factors

Social risk factors were the predominant vulnerability within White women, who were more likely to experience multiple disadvantage, mental health issues and social services involvement. There were also more White women who were not referred for additional support, most commonly regarding substance misuse or safeguarding concerns.

**Table 7: Identification and referral of social risk factors**

| Social risk factors | Black women N=36 | White women N=35 |
|---|---|---|
| Financial need | 1 | 1 |
| Insecure housing | 1 | 1 |
| Substance misuse | 1 | 3 |
| Criminal Justice involvement | 0 | 0 |
| Social services involvement | 2 | 5 |
| Learning/physical disability | 0 | 0 |
| Domestic violence | 1 | 1 |
| Mental health issues | 3 | 10 |
| Young (under 20 years) | 0 | 4 |
| Recent migrant (less than 1 year) | 4 | 1 |
| Difficulty speaking or understanding English | 4 | 2 |
| Smoking [note 1] | 2 | 8 |
| Number of social risk factors | | |
| None | 24 | 18 |
| One | 6 | 6 |
| Two | 5 | 7 |
| Three or more | 1 | 4 |

Note 1: Smoking is an additional risk factor not included in the Revolving Doors definitions.

It was noted that social risk factors were not recorded systematically within the maternity records of both groups and therefore there may have been limited identification and referral. Where women had multiple social risk factors there was a lack of multi-disciplinary team working and a failure to consider the woman's care from a holistic perspective.

**Vignette 4: Lack of holistic assessment of complex social risk factors**

A White British woman in her second pregnancy had a history of alcohol and substance misuse, and socio-economic deprivation. Safeguarding issues had been identified in her previous pregnancy. She was referred to the appropriate services, but did not meet the threshold for additional support in this pregnancy. An intrauterine death was identified when she presented with a third episode of reduced fetal movements. The review panel concluded there was a lack of holistic assessment of complex social risk factors that could have affected the pregnancy and family.

### Vignette 5: Poor multidisciplinary team working

An older, Black African, mother experienced an intrauterine death at term. None of her previous children were in her care. The maternity safeguarding team were involved early in pregnancy and she was supported by the mental health team. Her medication was stopped in early pregnancy. Her mental health became unstable in the third trimester and she was sectioned under the Mental Health Act. There was a lack of multidisciplinary team working between perinatal mental health and obstetric teams despite the midwives strongly advocating on her behalf. It was noted by the review panel that there was no recognition that an earlier joint mental health referral would have been appropriate and would have provided an opportunity to recommence medication which may have improved her care.

There was a greater number of White women who were not asked about domestic violence (n=4). Routine mental health enquiry, whether using the Whooley Questions for Depression Screening or another means, was evidenced less frequently in Black women during antenatal care (n=10) compared with six White women. Overall, there were fewer assessments noted in the postnatal period for both groups. The enquiry identified that for some women this contributed to suboptimal care, but was not likely to be related to the outcome.

### Table 8: Routine mental health assessments

| Stage of care pathway and evidence of mental health assessment | Black women N=36 | White women N=35 |
|---|---|---|
| Antenatal | | |
| Evidenced - Whooley questions | 20 | 21 |
| Evidenced – other | 5 | 7 |
| None evidenced | 10 | 6 |
| Unbooked | 1 | 1 |
| Postnatal | | |
| Evidenced - Whooley questions | 4 | 4 |
| Evidenced - other | 4 | 4 |
| None evidenced | 28 | 27 |

Female genital mutilation (FGM) is an issue for some Black populations. Despite national guidance that places responsibilities upon professionals to safeguard and support women and girls affected by FGM, there were instances of FGM not being identified or responded to appropriately, however the review panels did not consider this as having impacted upon the outcomes for either mothers or babies.

## 4.6. Engagement with maternity services

Access to routine maternity care was explored using timing of booking, acceptance of routine screening and the management of non-attendance at appointments. While the majority of non-attendances (DNAs) were followed up, there were also examples of this not being explored in any detail and a lack of personalised care being provided. Therefore, missed opportunities to improve access to care were identified as suboptimal care which was possibly relevant to the outcome.

### Table 9: Engagement with maternity services

| Issues relating to engagement with maternity services | Black women N=36 | White women N=35 |
|---|---|---|
| Unbooked pregnancy | 1 | 1 |
| First antenatal visit at 13 completed weeks' of gestation or later | 6 | 6 |
| Screening for trisomies offered and declined | 3 | 2 |
| Did not receive recommended number of antenatal visits for gestation [note 1] | 6 | 3 |
| Did Not Attend (DNA) two or more appointments | 4 | 2 |
| DNA policy in place but not followed | 2 | 1 |

Note 1: Includes one Black woman and one White woman whose pregnancies were unbooked.

### Vignette 6: Lack of sensitivity potentially resulting in poor engagement with maternity services

An older, multiparous Black African woman of Muslim faith booked her pregnancy in the first trimester. She had type 2 diabetes mellitus and FGM, was a smoker and needed interpretation services. Her family circumstances were also difficult, with a large family living in an overcrowded home.

Her diabetes care was suboptimal and poorly documented. Following an early preterm premature rupture of membranes at 16 weeks, the pregnancy continued until 29 weeks, when she underwent an emergency caesarean section. Her baby died the day after birth.

There was a lack of overview of her care and poor cultural sensitivity. She had a total of 25 antenatal appointments, and there was no consideration of her family circumstances or her religious background; one appointment was arranged during Eid. She did not attend appointments on a total of 10 occasions. The reasons for non-attendance were not explored in any detail and her language needs were not addressed.

Her postnatal recovery was difficult, with a significant abdominal hematoma and a very insensitive debrief.

Black women were more likely to experience barriers to accessing specific aspects of care that were offered (Table 10).

**Table 10: Barriers to accessing specific aspects of care**

| Type of barrier to access | Black women N=36 | White women N=35 |
|---|---|---|
| Self-discharge against advice [note 1] | 5 | 1 |
| Not taking medication [note 2] | 5 | 1 |
| Non-attendance at specialist appointments [note 3] | 5 | 3 |
| Total types of non-acceptance | | |
| One | 5 | 3 |
| Two | 2 | 1 |
| Three | 2 | 0 |

Note 1: 2 Black Caribbean, 3 Black African.
Note 2: 3 Black African, 1 Black Caribbean, 1 Black Other.
Note 3: 5 Black African.

## 4.7. Overall summary of quality of care and lessons to be learned

Evidence from the maternity records suggests there is variation and inconsistency in the recording of ethnicity, nationality and citizenship status which is likely to lead to a lack of personalised care which is kind and compassionate. There is conflicting and inconsistent documentation regarding language needs and the provision of interpreters was inadequate. Lack of independent interpretation services may have impacted upon women’s ability to make informed choices about their care, and there were multiple instances of family members and health care professionals being used as interpreters.

**Recommendations**

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 include 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.

The panels identified instances where services had not recognised safeguarding issues, mental health and complex social needs, and of those that were identified support was not always provided. A lack of nuanced care was identified for both groups of women and babies, notably a lack of holistic assessment, continuity and personalised care within the antenatal period that may have impacted on both outcomes and experiences.

**Recommendations**

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.

# 5. Issues along the care pathway

## 5.1. Introduction

Previous confidential enquiries have identified many issues with the quality of care provision along the care pathway. Although many recurring issues were found in this enquiry the focus here is to identify specific quality of care issues where differences were found when comparing the care provided to Black and White women and their babies.

## 5.2. Key findings

- Oral glucose tolerance tests were not offered to more eligible Black women (29%) compared with White women (3%)
- Poor management of hypertension was noted in the care of three Black women. No White women were identified with this issue.
- There was a failure to follow national vitamin D guidance for all eligible women in this review. The impact of this was far greater for the Black women as they were all eligible for higher dose vitamin D compared with only a small proportion of White women.
- Provision of information about reduced fetal movements was less common for Black women (47%) compared with White women (58%).
- Where there was sufficient time there was no evidence a partogram was completed for 64% Black women and 36% White women.
- When pain relief was requested during labour, there were similar proportions of women in both groups who did not receive pain relief within 15 minutes: 27% of Black women and 35% of White women.
- The standard of neonatal care provision was similar for both Black and White babies.
- Medication for lactation suppression was more likely to be offered and accepted by Black women (78%) than White women (46%).
- Post-mortem was carried out for 67% of Black and 51% of White stillbirths and neonatal deaths.
- Placental histology was carried out for the vast majority of Black (92%) and White (85%) stillbirths and neonatal deaths.
- Complete maternal and pregnancy information was provided for post-mortem for only 13% of Black babies and no White babies.
- Similar proportions of post-mortem and/or placental histology reports were felt to be lacking an adequate clinicopathological correlation for Black (25%) and White (22%) mothers and babies.
- Black parents were less likely to receive a follow-up letter directly addressed to them than White parents: 33% compared with 46%.

## 5.3. Antenatal care

There were a number of aspects of care where differences between the two groups were highlighted by the panels.

The screening of Black women for gestational diabetes mellitus (GDM) was inconsistent and did not follow guidance (NICE, SIGN). There were 24 births after 28 weeks in this group of women, seven (29%) of the Black women eligible were not offered an oral glucose tolerance test (OGTT) in line with guidance. Of the 29 White women who gave birth after 28 weeks, only one of the women eligible (3%) was not offered an OGTT.

NICE guidance recommends that pregnant women at high risk of pre-eclampsia are offered 75 to 150 mg Aspirin daily, from 12 weeks of pregnancy until the birth of their baby. Evidence from the enquiry panels indicated that this guidance was not followed for 7 out of 11 (63%) eligible Black women and 5 out of 7 (71%) eligible White women.

National guidance in effect at the time these women were pregnant indicated that Black women require a higher dose of vitamin D (25 micrograms or 1000 International Units per day). There was a failure to recognise this requirement for all the 32 eligible Black women in this enquiry, with none receiving this increased dose. This was also the case for the four White women who met the criteria for a higher dose of vitamin D, none of whom received it. Whilst the proportion of women affected by lack of compliance with this guidance was higher for the White women, the impact on the Black women was significantly greater as all Black women receiving antenatal care were eligible for the higher dose of vitamin D. Whilst a higher dose was recommended at the time, this guidance was subsequently withdrawn in April 2021. Women who are at particular risk of vitamin D deficiency, which includes women of Black ethnicity, may still be advised to take a higher daily dose of vitamin D, however.

The incidence of stillbirth and early neonatal death is known to be higher in women with hypertension. Three Black women had poor management of their hypertension which is likely to have impacted on their outcome. For example one woman had a blood pressure at booking of 188/106 that was not acknowledged or actioned. There are clear national guidelines for the management of hypertension in pregnancy, and escalation to senior medical staff for hypertensive planning should be easily available in each unit. Most women with hypertension can safely give birth at term or later preterm with appropriate treatment and management. There were no White women identified in the enquiry where this was an issue.

Previous enquiries have identified a failure to provide written information before 24 weeks gestation about what women should do if they are concerned about any reduced fetal movements (RFM), with discussion of RFM at each maternity contact after 24 weeks. Table 11 shows that this enquiry was no different, but with fewer Black women (16 of 34 (47%) eligible women) having appropriate discussions compared with White women (19 of 33 (58%) eligible women).

**Table 11: Information about reduced fetal movements**

| Information provided | Black women N=36 | White women N=35 |
|---|---|---|
| Written information about RFM by 24 weeks, and discussed at each subsequent appointment | 8 | 8 |
| Written information about RFM by 24 weeks, but not discussed at each subsequent appointment | 5 | 5 |
| No written information about RFM by 24 weeks, but discussed at each subsequent appointment [note 1] | 8 | 11 |
| No written information about RFM by 24 weeks, and not discussed at each subsequent appointment [note 2] | 15 | 11 |

Note 1: One White woman booked after more than 24 weeks.
Note 2: One Black woman booked after more than 24 weeks and one Black woman was unbooked. One White woman was unbooked.

## 5.4. Labour and birth

There was an inconsistent use of a partogram once labour was established that was more evident in Black woman than in the White comparator group. In the Black group of women, there was time to complete a partogram before birth for 25 women, yet a partogram was not filed in the notes for 16 of these women (64%). For the nine women that had partograms present, seven were fully completed and two were partially complete. This compares with the White group of women where there was time to complete a partogram before birth for 22 women, but these were not filed in the woman's notes in eight cases (36%). Ten White women had full partograms carried out and recorded, three were partially completed and one further partogram was filed but not completed.

Previous work has identified poor management of pain relief in Black populations, as this group have been wrongly considered to have a higher pain threshold than other people. The enquiry found that where pain relief was requested during labour, it was not given within 15 minutes for 7 out of 26 (27%) Black women and 6 out of 17 (35%) White women.

## 5.5. Neonatal care

Good neonatal practice was commented on by the enquiry panels in six of the pregnancies of Black women and 13 of the pregnancies of White women. This included women whose babies were stillborn, but who received input from the neonatal team as part of their antenatal care. There were similar numbers between the two groups of examples of good multidisciplinary team discussion and planning and building trust with families. However, instances of good documentation, a consultant being present at the birth and joint obstetric/neonatal follow-up were noted less commonly for babies born to Black women.

Suboptimal neonatal care was identified in three of the babies born to Black mothers (3 to 10 issues per baby) and four of the babies born to White mothers (2 to 12 issues per baby). In a further case a neonatal unit was reported to be 'full'; there was a subsequent lack of documentation regarding on-going management, including neonatal care, for this baby of a Black woman who was subsequently stillborn.

The suboptimal neonatal care identified was almost identical in type and number between the two groups of babies. It mirrors those highlighted in previous confidential enquiries and other independent reviews of perinatal services.

By far the commonest issue identified related to clinical management, particularly resuscitation and early thermal care, but also included delays in commencing antibiotic treatment for suspected sepsis with no differences between care provided for Black and White babies. In a number of babies this was compounded in several instances by a failure to seek or have access to prompt senior support. A lack of team leadership, including stepping back to obtain a 'helicopter view' of the care or expediting specialist referral was felt to have contributed significantly to the outcome for several babies. There were numerous instances of poor documentation (including prescribing). There was no clear difference in the small number of instances of poor communication between the two groups.

## 5.6. Ongoing care

The loss of a baby during pregnancy, or shortly afterwards, is a devastating event which can have significant long-term impacts on the health and wellbeing of the parents and their relationships with their wider network. Whilst health professionals cannot change the fact that their baby has died, compassionate, sensitive, personalised and parent-centred care can help a family come to terms with their loss and prepare for the future, including potential future pregnancies.

Whilst there may be subtle differences in how bereavement care is delivered, based upon gestation and the arrangements within a local maternity unit, there is a goal within the UK to offer the same level and quality of care to all parents who experience perinatal loss. The panels identified some differences in the expected standard of bereavement care which are noteworthy. Cabergoline (a medication commonly used to supress lactation) was more likely to be offered and accepted by Black women than White women: 78% (28 out of 36) versus 46% (16 out of 35). Cabergoline was not recorded as being offered to 18 White women and five Black women, and one further White woman and three Black women declined when offered.

## 5.7. Pathology

### Uptake and quality of post-mortem examinations

Post-mortem examination of a baby following stillbirth or neonatal death may provide a cause or partial explanation of death and information relevant to the management of subsequent pregnancies. Autopsy is acknowledged as the single most useful investigation, and provides information that either changes or significantly contributes to the clinical information in nearly half of cases. Histopathological examination of the placenta following stillbirth or neonatal death may also help provide an explanation as to why the death occurred, as well as information relevant to the clinical management of any subsequent pregnancies. Of the deaths reviewed, post-mortem was carried out for 24 (67%) of Black stillbirths and neonatal deaths, of which one was a coronial/procurator fiscal post-mortem and four post-mortems were limited external examinations. This compares with 18 (51%) post-mortems for the White stillbirths and neonatal deaths (including 3 coronial/procurator fiscal PMs). Placental histology was carried out for vast majority of Black (92%) and White (85%) stillbirths and neonatal deaths. Two stillbirths in each group did not have placental histology carried out. All except one Black stillbirth had their pathological examinations carried out by a specialist perinatal/paediatric pathologist.

**Table 12: Pathological examination**

| Type of pathological examination | Black women N=36 | Black women % | White women N=35 | White women % |
|---|---|---|---|---|
| Post-mortem | 24 | 67 | 18 | 51 |
| Full | 19 | 53 | 15 | 43 |
| Limited | 4 | 11 | 0 | 0 |
| Coronial/Procurator Fiscal | 1 | 3 | 3 | 9 |
| None | 12 | 17 | 17 | 49 |

| | | | | |
|---|---|---|---|---|
| Placental histology | 33 | 92 | 30 | 86 |
| Carried out by non-perinatal/paediatric pathologist | 1 | 3 | 0 | 0 |

Post-mortem and placental histology reports were assessed and scored against current guidelines, using a checklist, by the paediatric and perinatal pathologists on each enquiry panel. The quality of 13 out of 23 (56%) post-mortems and 15 out of 33 (45%) placental histology reports for Black babies was assessed as excellent or good compared with 12 out of 17 (71%) and 16 out of 29 (55%) for White babies, respectively.

### Table 13: Quality of post-mortem and placental histology reports

| Grading of post-mortem report [note 1] | Black women n=23 | Black women % | White women n=17 | White women % |
|---|---|---|---|---|
| Excellent | 5 | 22 | 6 | 35 |
| Good | 8 | 35 | 6 | 35 |
| Satisfactory | 6 | 26 | 3 | 18 |
| Poor | 4 | 17 | 2 | 12 |
| Grading of placental histology report [note 2] | Black women n=33 | Black women % | White women n=29 | White women % |
| Excellent | 10 | 30 | 3 | 10 |
| Good | 5 | 15 | 13 | 45 |
| Satisfactory | 13 | 39 | 7 | 24 |
| Poor | 5 | 15 | 6 | 21 |

Note 1: Two post-mortem reports (one Black, one White) were unavailable for review.
Note 2: One White placental histology report was unavailable for review.

### Lack of adequate clinical information for perinatal autopsy and placental examination

Whilst the vast majority of the pathology reports (placental and post-mortem) were of good quality (graded as excellent, good or satisfactory), and adhered to Royal College of Pathologists reporting guidelines, there was a general lack of adequate clinical information provided by clinical staff when requesting pathology, which hindered optimal clinicopathological correlation. Complete maternal and pregnancy information was provided for only 13% of Black post-mortems and for no White post-mortems. Most commonly missing maternal items were BMI (57% Black, 76% White) and family history (48% Black, 71% White). High proportions of pregnancy items were missing across both ethnicities and for the full range of required information, e.g. EDD, infection history, hypertension.

## 5.8. Follow-up appointment

To help parents understand why their baby died, and to prepare for a future pregnancy they need a clear, supportive and compassionate follow-up appointment. As discussed in the Section 4.4, there should be appropriate translation services provided and documented when required. The correct professionals need to be present (obstetricians and/or neonatologists as appropriate) plus support staff (such as a bereavement midwife or nurse). All the results need to be available. If follow-on investigations are required, they should be organised with appropriate follow-up (either another meeting or a letter). After the meeting, a letter summarising the discussion should be sent to the parents. The letter should cover the events leading to the perinatal loss, what was thought to be the cause including the results of any investigations, plans for future pregnancy and, if appropriate, advice regarding contraception. The letter should be written in a sensitive manner using plain language, explaining medical terms when necessary. It is considered best practice to address the letter to the parents directly. In this enquiry this was the case for fewer Black parents (33%) than White parents (46%). The GP can be written to separately, or copied into the parents' letter. If the family cannot attend the follow-up meeting, or decide not to attend, a further appointment may be offered and a clear letter to the parents and the GP should be written.

Whilst the quality of letters to parents was higher than in previous enquires, some were insensitive or over-medicalised. It was still less common for letters to be addressed directly to the parents rather than the GP.

### Table 14: Letters to parents summarising care

| Letters to parents summarising care | Black women N=36 | White women N=35 |
|---|---|---|
| Letter to parents | 12 | 16 |
| No letter to parents, letter to GP with parents copied in | 9 | 3 |
| Letter to GP only | 6 | 6 |
| No letter to parents or GP | 9 | 10 |

Most parents had a documented discussion about any plans for future pregnancies at some point during their postnatal care (26 Black, 23 White).

Nine Black women and 10 White women did not have a follow-up appointment. This includes a White woman whose appointment was booked for 13 weeks after her baby's death, and one Black woman whose appointment was booked for 16 weeks after her baby's death. Both women did not attend these appointments. For parents where the follow-up appointment did not happen, letters were sent to two sets of Black parents but no White parents.

### 5.9. Overall summary of quality of care and lessons to be learned

The review panels identified a number of key issues along the care pathway, where the quality of care provision differed between the Black and White groups. These highlight the need for ensuring all women receive personalised care which is sensitive to their individual circumstances. Training should be developed to address this issue.

**Recommendation**

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.

## 6. Reviews of baby deaths

### 6.1. Introduction

A local review of care when babies die fulfils several purposes. Firstly, it provides information for bereaved parents about the quality of care they received, an assessment of whether different care may have prevented the death and information for future pregnancy planning. Secondly, it provides an opportunity for any questions or concerns parents may have about their care to be considered in the course of the review and for their specific questions to be addressed. Finally, the review findings provide an opportunity for learning and the identification of service quality improvements to improve care for future mothers and babies.

Previous MBRRACE-UK confidential enquiries and the RCOG Each Baby Counts programme consistently identified issues with the quality of local reviews when perinatal deaths occurred. They found many instances where there was no evidence that a review had taken place. When reviews were conducted a range of generally non-standardised review methods were used; often only some elements of care were reviewed and not all stages of the care were considered; and the quality of many reviews was as a consequence very poor.

### 6.2. Introduction of the Perinatal Mortality Review Tool

This is the first MBRRACE-UK confidential enquiry conducted after the introduction of the national Perinatal Mortality Review Tool (PMRT). The PMRT is designed to support the local review of care when a baby death occurs providing a framework for a standardised, robust review of all elements of care for every perinatal death from pre-conception through pregnancy, labour, birth, neonatal care, bereavement care and postnatal investigations. Launched in 2018 the PMRT was used to review 83% of all perinatal deaths in England, Wales and Scotland in 2019, the year in which the babies included in this enquiry died. Services in Northern Ireland adopted the PMRT in autumn 2019. The second year of the Maternity Incentive Scheme in England set the standard for Safety Action One (SA1) in 2019, specifying that a review of care using the PMRT should be started within four months of each death for 95% of all perinatal deaths in that year. In Scotland, all Health Boards are expected to use PMRT in line with Maternity and Neonatal (Perinatal) Adverse Event Review Process.

The deaths of 66 of the 71 babies in this enquiry were reviewed locally using the PMRT. The care of two babies of Black ethnicity that were stillborn and three babies of White ethnicity who died in the neonatal period were not reviewed.

### 6.3. Key findings

- Parent engagement is a key part of the local review of care. Regardless of ethnicity, no parents with identified language barrier communicated any questions or concerns about their care to the local review team and likely indicates the continuing theme of lack of available interpretation services
- In this second year following the launch of the PMRT, a substantial proportion of reviews in this enquiry were carried out either by single professionals or by too few professionals of the correct clinical speciality to constitute a multidisciplinary review; this was not affected by ethnicity.
- The holistic grading of care of the mother and baby following local review was not affected by ethnicity, but was more

positive than the grading reached by the confidential enquiry panels.

## 6.4. Parent engagement in the local review

According to the PMRT reports reviewed by the enquiry, where a PMRT review had been undertaken, all parents had been informed that a local review of care would take place. They were also all invited to communicate any questions or concerns they had about their care and that of their baby. A small number of parents took this opportunity to express their gratitude for the care they had received. The majority of parents either explicitly indicated they had no questions or concerns to raise or they never communicated any questions or concerns to the hospital. Parents with an identified language barrier, regardless of ethnicity, were all in the latter group. About a third of parents of both groups of babies asked questions and/or expressed concerns about their care and the nature of these questions and/or concerns were similar across the two ethnic groups.

## 6.5. Quality of the reviews

As part of the confidential enquiry the report of each PMRT review carried out was considered by the enquiry panel. Overall only five of the 66 reviews were highlighted as being of "good" quality, with the remainder assessed as being of "poor" quality in general, not carried out by an adequate multidisciplinary team and/or failed to address parents' questions or concerns. There was no difference by ethnicity of the baby.

Examples of poor quality reviews included a failure to:

- address parents' questions and/or concerns;
- assess the quality of scan images for a growth restricted baby who had not been identified as such in utero;
- recognise that appropriate interpretation services had not been provided;
- identify that the vulnerabilities and safeguarding needs of a young mother had not been addressed during her pregnancy and postpartum;
- incorporate findings from an earlier rapid review of care which identified concerns with care;
- identify that a mother eligible for an oral glucose tolerance test (OGTT) had not been offered an OGTT;
- consider the findings of the post-mortem, which were available, whilst undertaking the review of care;
- reach a conclusion about the cause of death despite having sufficient information available to do so.

The number of poor quality reviews was slightly greater for the babies of White than Black ethnicity, although the range of elements identified as poor quality was not notably different. The lack of, or poor quality of, interpretation services was identified as an issue with care together with action plans relating to providing interpretation services and written material in other languages for only half of the women with an identified language barrier.

## 6.6. Multidisciplinary review groups

Eleven reviews of the care of babies of Black ethnicity and seven reviews of the babies of White ethnicity were carried out by a review group which included less than five members; this is too few to meet the recommended standard for a multidisciplinary group. The median number of members of the review panel was six for both groups of babies. External members were present for eight of the reviews of babies of Black ethnicity (with two external members for four reviews) and five of the reviews of babies of White ethnicity.

Examples of review groups which were not multidisciplinary included:

- reviews carried out by a single professional;
- review panels which did not include an obstetrician;
- review panels consisting only of midwives;
- review panels consisting of a single obstetrician and two midwives where the obstetricians were involved in providing the care being reviewed;
- care provided by three different hospitals but the review was carried out by only one hospital;
- despite the particular circumstances a wider group of professionals with specific and essential expertise were not present at the review.

**Vignette 7: The impact of a non-multidisciplinary review group on local review quality**

A White woman in her third pregnancy self-referred at 23 weeks' gestation with mild back pain and a mild pyrexia. After a wait of 2 hours for an initial midwifery assessment she waited 4 hours for an obstetric review. On examination she was found to be 4 cm dilated with bulging membranes. An initial plan for active intervention was made and she was commenced on magnesium sulphate, IV antibiotics and was given steroids. She was seen by a member of the neonatal team the following day. The next day she had progressed to 8cm and her membranes had ruptured. She remained on labour ward for a further four days, with two consultant obstetric reviews per day and no change in the plan of watchful waiting until her baby was confirmed as having died in utero at 24 weeks. After her baby had died, she waited two and a half hours for a confirmation scan. Following the birth, she had a manual removal of placenta in theatre and a two litre postpartum haemorrhage. The parents did not wish for a post-mortem or placental histology.

The PMRT was carried out by a panel of midwifery staff only, and none of the parental questions were directly addressed. No specific issues relevant to the outcome were identified and the only learning point highlighted was that the mother's reflexes were not tested four-hourly when magnesium sulphate was being administered. Grading of care was given as B: "identified care issues which would have made no difference to the outcome for the baby."

The enquiry panel concluded that there had been a failure to discuss modifying this mother's plan of care during the five days she was on labour ward when her clinical circumstances were changing. Given these changes it would have been appropriate to offer to expedite the birth that was clearly imminent when her baby was still alive. Her developing sepsis was poorly managed. She was in painful urinary retention due to the position of her baby; when she was catheterised 1500mls drained. There was no evidence that her fluid balance was monitored or evidence of efforts to maintain an appropriate fluid balance. There was no plan to scan the baby to obtain an estimated fetal weight to further inform the planning of care, and to provide an insight into the possible outcome for her baby once admitted for neonatal care.

The enquiry panel concluded that the local PMRT review lacked insight as a consequence of a complex obstetric case being reviewed by midwifery staff only. There was also a failure to address the parental questions which highlighted the main issues relevant to the outcome.

## 6.7. Grading of care

The grading of care used by the PMRT is not exactly the same as the holistic grading of care used for the confidential enquiry panels, but it is comparable. For 64% of the PMRT reviews the pregnancy, labour and birth care was graded A, as having no issues with care identified; 21% were graded as B, issues with care which would have made no difference to the outcome for the baby; and 15% were graded as C/D where issues with care were identified with may or were likely to have made a difference to the outcome respectively. Thus, overall 36% of reviews identified that improvements in care were needed. The grading did not vary by ethnicity of the baby. Only a small number of babies received neonatal care and the grading of their care was also not different by ethnicity.

When the gradings of care from the PMRT were compared with those from the confidential enquiry panels, there were clear differences. When reviewed by the enquiry panels, the care of the baby was graded as (1) good with no improvements identified for 14% of babies of Black ethnicity and 23% of babies of White ethnicity. The care was graded as (2) improvements in care which would have made no difference to the outcome for 44% of Black babies and 29% of White babies; and as (3) improvements in care which may have made a difference to the outcome for 42% and 49% of babies respectively. Thus, overall in 85% of the enquiries into the care of Black babies' and 78% of White babies' improvements in care were identified.

## 6.8. Overall summary of the PMRT reviews and lessons to be learned

There was very little difference between the local reviews of care for the babies of Black and White ethnicity other than a slightly larger number of poor quality reviews carried out for the babies of White ethnicity, although the ways in which they were poor quality were not particularly different between the two groups.

Parent engagement is an essential part of the local review process. Mothers are the only individuals present for the entirety of their pregnancy and know what happened at every stage; most will also be present for most of the neonatal care their baby receives. Parents must be listened to and to have their questions and concerns addressed; this did not happen in all instances in the care reviewed in this enquiry. Parents' questions also have the capacity to ensure review panels focus on crucial aspects of care and challenge the 'confirmation bias' of panel members. Not only is it important that parents receive the information they want and need, answering their questions will also help in the organisational learning needed to improve care and outcomes for the future.

Parents unable to speak and/or read English are less likely to be able express any question or concerns they may have about their care unless efforts are made to provide appropriate interpretation services. Regardless of ethnicity, none of the parents with an identified language barrier included in this enquiry had provided any comments or questions about their and their baby's care prior to the local review being undertaken. Parents' needs for interpretation services was identified in only half of the reviews where it was actually an issue. The local review is one of the final stages of care provided to bereaved families. As illustrated earlier in the report, services yet again failed those parents unable to speak English. By not supporting parents to express their need for information we fail to give them a voice thereby perpetuating barriers and inequalities of access to this final stage of care for these parents.

Every review needs to be carried out by a multidisciplinary panel to ensure that all aspects of care are adequately assessed by professionals with the requisite expertise to do so. This enquiry covered the period of the second year following the introduction of the PMRT when trusts and health boards were still in the embedding phase of its use. A substantial proportion of reviews in this enquiry were carried out either by single professionals or by too few professionals on the panel to constitute a multidisciplinary review. The proportions were in line with national figures for that year and did not differ by ethnicity. Members external to the trust or health board provide a 'fresh pair of eyes' and are able to provide challenge to potential 'group think'. It was heartening to see that a reasonable number of reviews had at least one external member present with the proportion greater than the national figures for the same year

The grading of care from the PMRT reviews was not affected by the ethnicity of the baby and generally care was graded as good for 64% and with improvements in care which may or may not have made a difference to the outcome identified for 36%. In contrast the grading by the confidential enquiry panels found a greater proportion where improvements were identified as well as a difference by ethnicity with a greater proportion of improvements identified in the care of babies of Black ethnicity (85%) compared with babies of White ethnicity (78%). We have found a similar contrast with findings in the past when comparing review findings with those of the MBRRACE-UK confidential enquiries, and this difference emphasises the importance of having external professionals as members of local PMRT review panels.

**Recommendations**

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, Northern Ireland Public Health Agency, and the RCOG, RCM, BAPM, RCPath.