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 Asian 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
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Chelsea and Westminster Hospital NHS Foundation Trust
University of Oxford
Oxford Population Health NPEU

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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.

Design by: Ian Gallimore

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Comparing the care of Asian and White women whose babies died

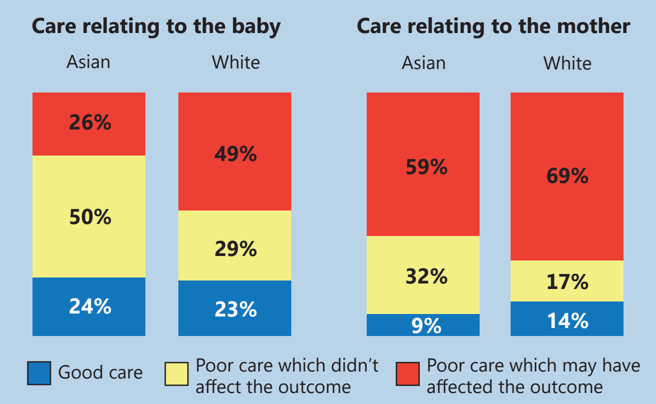
MBRRACE-UK
Mothers and Babies: Reducing Risk through Audits and Confidential Enquiries across the UK

Baby deaths in 69 pregnancies reviewed

34 Asian women

35 White women

Medical notes reviewed by clinical experts



Women's ethnicity, nationality and citizenship status was not always correctly written in the notes.	All women should be asked about their ethnicity, nationality and citizenship status, and it should be written in the her notes. Care should be planned based on each woman's specific needs.
When a woman's first language wasn't English and she needed an interpreter, this wasn't always provided. More Asian women needed an interpreter.	Women should be offered information about maternity care in different ways. An interpreter should be offered at each appointment, if the woman needs one 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 offered if it is needed.
Asian women were more likely to decline screening for chromosomal conditions when it was offered. Almost all White women chose to accept the offer of screening.	Women should be given information about antenatal screening tests, translated where necessary. If a woman chooses to have any of the tests, she should be offered an appointment to talk about the results and her future choices.
Blood tests to check for gestational diabetes were not offered to 1 in 5 Asian 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 Asian women, should be offered a test between 24 and 28 weeks of pregnancy.
All the Asian women should have been offered a high dose of Vitamin D to take during their pregnancy, but only 1 in 10 were.	All women should be offered Vitamin D to take during pregnancy, and women with darker skin or a BMI over 30 should be offered a higher dose.
Bereavement care was good for most parents, but White women were more likely to be seen by a midwife once they had left hospital.	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 personalised letter summarising what they talked about. Asian 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).	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 14 (41%) Asian women and four (11%) White women citizenship status was not recorded. 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. The predominant vulnerability within the Asian group was language difficulties. English was not the first language for 13 (38%) of the women within the Asian group and four (11%) women within the White group. Interpretation services were recorded as being required for nine Asian women and two within the White group (Eastern European), but were not consistently documented as being provided within any of the notes, with three Asian women having no interpreter provision. Possible language needs were not identified for an additional three Asian women. For several women healthcare professionals were used as interpreters. Panel reviews identified there were significant or major language issues, which were probably or almost certainly relevant to the outcome for five Asian women and two White women. **(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)** Except for one set of parents who sent positive comments about their care, all parents with an identified language barrier, regardless of ethnicity, did not indicate if they had questions or concerns. **(Section 6.4)** More mothers of babies of Asian rather than White ethnicity had an identified language barrier. 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 language for 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. Social risk factors were recorded as being present less within the Asian groups, with evidence of inconsistent identification and referral across both groups. Many of these social risk factors were not recorded systematically within maternity records, and there was variation as to what was recorded between the maternity notes. It is plausible that language barriers limited enquiry, and therefore identification, particularly in the Asian women. Within both groups there were small number of women for whom it was not recorded whether they had been asked about domestic violence. There were small numbers of both Asian and White women in whom the panels identified social risk factors which did not appear to have been identified by the clinical teams, and who were not referred for additional support, most commonly regarding substance misuse or safeguarding concerns. Within the White group there were five (14%) women where the panel reviews identified safeguarding and complex social needs as a significant or major

Recommendation	Target audience	Supporting evidence
		issues which were probably or almost certainly relevant to the outcome. **(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.	Engagement with maternity services was explored using timing of booking, accepting routine screening and whether the women was followed up following DNAs. 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. Barriers to accessing specific aspects of maternity care were identified in one Asian Pakistani woman who did not attend a specialist appointment, and four White women (one woman who self-discharged against advice and did not take prescribed medicines, and three other women who did not attend a specialist appointment). **(Section 4.6)**
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.	Engagement with maternity services was explored using timing of booking, accepting routine screening and whether the women was followed up following DNAs. 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. Barriers to accessing specific aspects of maternity care were identified in one Asian Pakistani woman who did not attend a specialist appointment, and four White women (one woman who self-discharged against advice and did not take prescribed medicines, and three other women who did not attend a specialist appointment). **(Section 4.6)**
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.	Engagement with maternity services was explored using timing of booking, accepting routine screening and whether the women was followed up following DNAs. 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)** Except for one set of parents who sent positive comments about their care, all parents with an identified language barrier, regardless of ethnicity, did not indicate if they had questions or concerns. **(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.	Not all parents had been informed that a local review of care would take place and this was the same for the two different ethnic groups. Those who had been informed were 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; there were more parents of babies of Asian than White ethnicity in this group. Except for one set of parents who sent positive comments about their care, all parents with an identified language barrier, regardless of ethnicity, did not indicate if they had questions or concerns. About a third of parents of babies of White ethnicity asked questions and/or expressed concerns about their care whereas it was about a sixth of parents of babies of Asian ethnicity. The types of questions/concerns were qualitatively more detailed from the parents of babies of White ethnicity. **(Section 6.4)**

Recommendation	Target audience	Supporting evidence
		More mothers of babies of Asian rather than White ethnicity had an identified language barrier. The lack of, or poor quality of, interpreter services was identified as an issue with care together with action plans relating to providing interpretation services and written material in other language for half of the women with an identified language barrier. The confidential enquiry panels identified two specific reviews where the parents asked pertinent questions about critical elements of their care which were also identified by the confidential enquiry panel members as being critical to the outcome for the baby. The local review groups neither identified these critical issues nor addressed the parents' questions. Had they done so, the confidential enquiry panel members felt the PMRT conclusions and subsequent actions to improve future care would have been different. **(Section 6.5)**
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.	Thirteen reviews (38%) of the care of babies of Asian ethnicity and seven reviews (22%) 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 nine of the reviews of babies of Asian ethnicity and five of the reviews of babies of White ethnicity. **(Section 6.6)**

MBRRACE-UK Perinatal Confidential Enquiry

A comparison of the care of Asian and White women 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 Asian 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 reference 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 Asian 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 Asian or Asian British ethnicity were at 57% increased risk of stillbirth and 59% 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 Asian 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 Asian 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 stillbirths and neonatal deaths for Asian 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 Asian 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 Asian and White women, in order to investigate the role of ethnicity in the increased rates of stillbirth and neonatal death for the Asian population. Specific areas for enquiry were developed in consultation with the enquiry stakeholder group and the Topic Expert Group (see Acknowledgements). Previous enquiries have reported quality of care issues along the care pathway that may be of relevance to one or both ethnic groups. In this report, these issues are primarily reported where a difference is found between Asian 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 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 identify 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 comprised health professionals from Asian, Black, White and mixed backgrounds.

As in previous enquiries the focus was on both good and poor quality care comparing care provision for Asian 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 Asian (Asian Bangladeshi, Asian Indian, Asian Pakistani, or Other Asian) 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 34 Asian 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 (217 Asian, 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 Asian 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 as well as baby characteristics for either the Asian or White groups (see the characteristics tables for full details). We therefore concluded that the results from this enquiry are representative of all stillbirths and neonatal deaths to mothers who are Asian 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 Asian 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 Asian 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 34 Asian 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 Asian 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 Asian 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 26% of Asian women and 49% of White women.
- Improvements in care were identified which may have made a difference to the outcome for the mother in 59% of Asian women and 69% of White women.
- Major or significant issues were found for antenatal care provision for 73% of Asian women compared with 69% of White women.
- 44% of Asian women and 54% of White women had major or significant care issues during postnatal and bereavement care.

- 27% of Asian mothers and babies and 46% of White mothers and babies had major or significant issues identified with respect to pathology.
- 65% of Asian and 66% of White parents had major or significant issues identified at follow-up or 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 Asian babies and mothers	Babies N=34	Babies %	Mothers N=34	Mothers %
Good care; no improvements identified	8	24	3	9
Improvements in care identified which would have made no difference to outcome [note 1]	17	50	11	32
Improvements in care identified which may have made a difference to outcome [note 1]	9	26	20	59
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 26% of Asian 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 59% of Asian mothers and 69% of White mothers. Good care throughout the care pathway was noted for similar proportions of Asian and White babies: 24% and 23% respectively, with slightly lower levels of good care noted in terms of outcomes for both Asian (9%) and White (14%) mothers.

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 mother and baby who had excellent care throughout the whole of the care pathway except for one element. Alternatively, a mother and baby 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 mother and baby 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 Asian and White pregnancies were determined by the panels to have major or significant issues during this period: 73% for Asian pregnancies compared with 69% of White pregnancies. Major or significant care issues during labour and birth, resuscitation and neonatal care were identified for around half of both Asian and White mothers and babies. However, the numbers of babies who received resuscitation or neonatal care were small due to the low numbers of neonatal deaths in each group. During postnatal and bereavement care 44% of Asian women received care graded with major or significant issues compared with 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 27% of Asian mothers and babies being graded as having major or significant issues compared with 45% of White mothers and babies. High proportions of both Asian (65%) and White (66%) families had major or significant issues identified at follow-up or review of their care and that of their babies.

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

Quality of care issues: Asian	Antenatal N	Antenatal %	Labour & Birth N	Labour & Birth %	Resuscitation N [note 1]	Resuscitation %	Neonatal N [note 1]	Neonatal %
None	7	21	12	35	7	50	7	50
Minor	2	6	3	9	2	14	0	0
Significant	13	38	13	38	1	7	4	29
Major	12	35	6	18	4	29	3	21
All	34	100	34	100	14	100	14	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 affecting the outcome for the mother: point on the care pathway and mother's ethnicity**

Quality of care issues: Asian	Postnatal & bereavement N	Postnatal & bereavement %	Pathology N	Pathology %	Follow-up & review N	Follow-up & review %
None	17	50	23	68	9	27
Minor	2	6	2	6	3	9
Significant	8	24	5	15	6	18
Major	7	21	4	12	16	47
All	34	100	34	100	34	100
Quality of care issues: White	Postnatal & bereavement N	Postnatal & bereavement %	Pathology N	Pathology %	Follow-up & review N	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 (Table 4). For each point on the care pathway where major or significant issues were identified one point was allocated and therefore each mother and baby pair could 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. There were small differences between the two groups with 32% of Asian mothers and babies scoring 4 or more compared with 40% of White mothers and babies. 47% of Asian mothers and babies scored 2 or less, compared with 34% of White mothers and babies.

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

Total score [note 1]	Asian N=34	Asian %	White N=35	White %
0 – No major or suboptimal care issues at any point on the care pathway	2	6	4	11
1	7	21	3	9
2	7	21	5	14
3	7	21	9	26
4	7	21	10	29
5 – Major or suboptimal care issues at all points on the care pathway	4	12	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 Asian and White mothers and babies. Along the care pathway, major or significant issues with care were similar for Asian mothers and babies compared with White mothers and babies at all points of the pathway except for pathology and postnatal and bereavement care where there were more significant and major issues identified for White mothers and babies compared with Asian mothers and babies.

4. Vulnerabilities identified in Asian and White women

4.1. Introduction

The MBBRACE-UK perinatal confidential enquiry reviewed the care of 34 Asian women (three Asian Bangladeshi, 10 Asian Indian, 18 Asian Pakistani and three Asian Other (one Syrian, one Iranian and one Kurdish (Iraq)) and 35 White women (including four Eastern European). 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 required it, with inappropriate use of family members and healthcare professionals.
- Social risk factors were recorded as being present less for the Asian women, with evidence of inconsistent identification and referral across both groups.
- Access to care and engagement (late booking, number and follow-up of non-attendance) was similar between Asian and White women. However, more Asian women declined routine combined screening.
- 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 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 14 (41%) Asian women and four (11%) White women citizenship status was not recorded.

Table 5: Citizenship status

Citizenship status	Asian women N=34	White women N=35
UK Citizen	15	30
EU Citizen	0	1
Non-EU Citizen	2	0
Indefinite leave to remain	2	0
Refugee	1	0
Not documented	14	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. The predominant vulnerability within the Asian group was language difficulties. English was not the first language for 13 (38%) of the women within the Asian group and four (11%) women within the White group. Interpretation services were recorded as being required for nine Asian women and two within the White group (Eastern European), but were not consistently documented as being provided within any of the notes, with three Asian women having no interpreter provision. Possible language needs were not identified for an additional three Asian women. For several women 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.

Panel reviews identified there were significant or major language issues, which were probably or almost certainly relevant to the outcome for five Asian women and two White women.

Table 6: Identification of language needs and interpreter provision

Language needs	Asian women N=34	White women N=35
First language not English (all)	13	4
First language not English, and difficulty in reading or speaking English	10	2
First language not English, and required an interpreter [note 1]	9	2
Trained interpreter or language line used at any point in the care pathway	6	2
Antenatal	4	2
Birth plan	2	2
Intrapartum	3	1
Neonatal [note 2]	0	0
Postnatal	3	1
Follow-up	2	1
Appropriate provision at every contact with services	0	0
No trained interpreter or language line used	3	0

Note 1: Five Asian Pakistani, two Asian Indian and two Asian Other (one Syrian, one Iraqi) women required an interpreter. Two White Eastern European women required an interpreter.
Note 2: Where an interpreter was required, 2 out of 6 Asian babies and no White babies received 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: Failure to ensure the woman's understanding of language and processes

A non-English speaking, Kurdish woman from Iraq in her third pregnancy who booked at 12 weeks. It was identified she required interpretation services for all her appointments. She was asked to book her own follow-up appointment after booking but did not understand the process. An appointment was therefore not made, and as a result, appropriate DNA policies were not activated. She was not seen again until she attended maternity services at 29+1 as an emergency. She was seen and discharged but a full assessment was not undertaken at that opportunity. When that was undertaken by her community midwife two weeks later an appropriate urgent referral was made for an ultrasound scan. This took place 72 hours later and sadly the baby had died. No follow-up appointment was documented.

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

Vignette 2: Good continuity of care for a woman with limited English

An Asian Pakistani woman in her first pregnancy was assessed as requiring interpretation services at her booking appointment. The anomaly scan identified early onset growth restriction and she was appropriately referred to the local fetal medicine team. Good continuity of care was provided by both the fetal medicine consultant and the fetal medicine midwife, who could speak Urdu with both the parents and the wider family when requested. Toward the end of the second trimester the fetal medicine scans identified a worsening prognosis. Following the administration of steroids and a plan for birth an intrauterine fetal death was identified. Bereavement investigations and the benefits of post mortem were discussed with the parents by the same team.

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. Social risk factors were recorded as being present less within the Asian groups, with evidence of inconsistent identification and referral across both groups. Many of these social risk factors were not recorded systematically within maternity records, and there was variation as to what was recorded between the maternity notes. It is plausible that language barriers limited enquiry, and therefore identification, particularly in the Asian women.

Table 7: Identification and referral of social risk factors

Social risk factors	Asian women N=34	White women N=35
Financial need	0	1
Insecure housing	1	1
Substance misuse	1	3
Criminal Justice involvement	0	0
Social services involvement	0	5
Learning/physical disability	1	0
Domestic violence	0	1
Mental health	2	10
Young (under 20 years)	1	4
Recent migrant (less than 1 year)	0	1
Difficulty speaking or understanding English	10	2
Smoking [note 1]	1	8
Number of social risk factors		
None	21	18
One	9	6
Two	4	7
Three or more	0	4

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

Within both groups there were small number of women for whom it was not recorded whether they had been asked about domestic violence. There were small numbers of both Asian and White women in whom the panels identified social risk factors which did not appear to have been identified by the clinical teams, and who were not referred for additional support, most commonly regarding substance misuse or safeguarding concerns. Within the White group there were five (14%) women where the panel reviews identified safeguarding and complex social needs as a significant or major issues which were probably or almost certainly relevant to the outcome.

Vignette 3: Lack of further investigation of potential safeguarding concerns

A teenage Bangladeshi woman in her first pregnancy disclosed at booking a previous history of cannabis use. There was no further discussion following this disclosure and no option of a referral to substance misuse services or additional toxicology screening in pregnancy. Her partner was older than her and there was no further enquiry during her pregnancy about her personal and social circumstances. Early in the third trimester, following a prolonged pre-labour rupture of membranes and a subsequent emergency caesarean section, her baby died shortly after birth. The parental debrief appointment was delayed as the mother was now resident in a women's refuge.

Evidence of routine mental health enquiry, whether using the Whooley Questions for Depression Screening or another means, was more common in the antenatal period, and was evidenced equally in both groups. There was very little evidence of routine enquiry in the postnatal period in 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	Asian women N=34	White women N=35
Antenatal		
Evidenced - Whooley questions	15	21
Evidenced – other	12	7
None evidenced	5	6
Not assessed (Unbooked)	2	1
Postnatal		
Evidenced- Whooley questions	0	4
Evidenced - other	4	4
None evidenced	30	27

4.6. Engagement with maternity services

Engagement with maternity services was explored using timing of booking, accepting routine screening and whether the women was followed up following DNAs. While late booking (13 weeks or later) was similar between the groups, routine combined screening was declined by ten Asian and two White women.

Table 9: Engagement with maternity services

Issues relating to engagement with maternity services	Asian women N=34	White women N=35
Unbooked pregnancy	2	1
First antenatal visit at 13 completed weeks' gestation or later [note 1]	9	6
Screening for trisomies offered and declined [note 2]	11	2
Did not receive recommended number of antenatal visits for gestation [note 1]	10	4
Did Not Attend (DNA) two or more appointments	4	2
DNA policy in place but not followed	1	1

Note 1: Includes two Asian woman and one White woman who were unbooked.
Note 2: A further three Asian women were not offered antenatal and screening, because they were unbooked (n=2) or booked late (n=1). A further four White women were not offered antenatal screening, because they were unbooked (n=1) or booked late (n=3).

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.

Vignette 4: Lack of continuity despite social risk factors and multiple attendances

An Asian Pakistani woman booked her pregnancy late in the second trimester. An anomaly was identified on scan and subsequently managed by a fetal medicine unit in an adjoining region. The mother's spoken English was poor and her husband insisted on acting as interpreter. During an antenatal counselling visit, the husband's brother was also present and the mother chose to leave the room as she did not want to take part in the counselling. The family attended eight fetal medicine appointments across two hospitals during the pregnancy. She missed three of her routine appointments and there was no evidence that efforts had been made to streamline her antenatal care.

She presented to the maternity assessment unit in early labour and despite a clear plan in place for a postnatal cardiac assessment following birth for her baby she was discharged home. The reviewing team recognised that language barriers and continuity may have prevented the family from expressing their concerns about the early labour discharge home. Her baby was subsequently born in the wrong place for appropriate assessment. The baby died a few days after birth.

Barriers to accessing specific aspects of maternity care were identified in one Asian Pakistani woman who did not attend a specialist appointment, and four White women (one woman who self-discharged against advice and did not take prescribed medicines, and three other women who did not attend a specialist appointment).

Vignette 5: Barriers to accessing specific aspects of care

A White Eastern European woman in her first pregnancy booked in her third trimester following initial antenatal care in her home country. A scan at 25 weeks identified a chromosomal anomaly, and when she arrived in the UK a further scan was suggestive of Trisomy 13. Palliative care and the support of a local hospice was discussed. Towards the end of her pregnancy, she developed pre-eclampsia but declined admission. There was also evidence of medication not being taken and she was resistant to the recommended plan for blood pressure monitoring. She laboured spontaneously at 36 weeks and her baby was stillborn. Following the birth there was evidence of good telephone bereavement support.

4.7. Congenital anomalies

Ten Asian women's babies died due to a congenital anomaly, compared with four White women. Of these ten women, three were in close-relative marriages and also had a previous child with a genetic disorder. A further two women were in an other-relative relationship. In total, seven Asian women were in close-relative marriages and four were in other-relative relationships, and four Asian women had a prior child affected by a genetic disorder. Three of these women were reviewed by a clinical geneticist during pregnancy, but there was no evidence of prior assessment. There were no White women in close-relative or other-relative relationships, or with a previous child with a genetic disorder.

Vignette 6: Inappropriate place of birth for a baby with complex congenital anomalies

An Asian Pakistani woman booked late in the second trimester, and the anomaly scan identified a complex cardiac abnormality. She subsequently presented in early labour to her local hospital. Antenatal transfer to a cardiac unit in an adjoining region (where she had been seen by the fetal medicine service) was not considered.

The baby was born in good condition and was transferred to the neonatal unit. The parents were informed that transfer to the cardiac unit would then be undertaken, but this did not happen due to cot shortages. The baby remained stable for around 30 hours before developing tachypnoea. Over the following 6 hours the abdomen became distended; a urinary catheter was inserted and it was only at this point an imperforate anus was noted.

Paediatric surgical advice was sought, and transfer to the cardiac unit was delegated to the most junior member of the paediatric team. There followed multiple conversations with two other neonatal transfer services, before an appropriate bed was located in another region and transfer undertaken.

Following surgery to alleviate the abdominal distension, further investigations determined that the cardiac lesion was inoperable. The baby was returned to the children's ward at the local hospital for palliation. The analgesia regime prescribed by the cardiac unit had been discussed with the palliative care team from the baby's local region but exceeded the experience of the local paediatric team. The palliative care team provided little direct support to the paediatric team.

Following transfer to the baby's local unit, the family wished to reconsider the decision to provide only palliative care. There followed multiple discussions with the local paediatricians, during which time the baby began to deteriorate significantly. A degree of non-invasive respiratory support was commenced, but the baby continued to deteriorate. Ultimately the family agreed that further escalation of treatment was not in the baby's best interests. The baby died a few days after birth.

There were examples of good, compassionate care when a congenital anomaly was diagnosed.

Vignette 7: Compassionate care following a diagnosis of a lethal congenital anomaly

An Asian Indian woman with no documented language issues booked in her first trimester and was assessed as requiring high risk care. She had an increased risk of Trisomies 13 and 18 at the nuchal translucency ultrasound scan, but declined further diagnostic testing and remained under the care of the fetal medicine unit. At 24 weeks, intrauterine growth restriction and congenital diaphragmatic hernia was diagnosed. The mother consented to an amniocentesis and Trisomy 18 was confirmed. Plans for comfort care of the baby were made alongside the neonatal team in view of the diagnosis and poor prognosis. She developed polyhydramnios and her membranes spontaneously ruptured at 34 weeks. She was admitted to hospital and a plan was made to induce labour if she did not give birth spontaneously within 24 hours. The baby was born spontaneously later that day. Comfort care was provided at birth and the baby died two hours later. There was culturally sensitive bereavement care provided while the mother remained in hospital.

4.8. Overall summary of quality of care and lessons to be learned

Evidence from the maternity records suggests 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 the women's ability to make informed choices about their care and there were multiple instances of family members and healthcare 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.

Women were identified 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 recognised within both groups, 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 Asian and White women and their babies.

5.2. Key findings

- Oral glucose tolerance tests were not offered to more eligible Asian women (22%) compared with White women (3%)
- There was a failure to follow national vitamin D guidance for all White and most Asian (90%) eligible women in this review. The impact of this was far greater for the Asian women, as they are all eligible for high dose vitamin D compared with a only small proportion of White women.
- Uptake of antenatal screening for chromosomal conditions was lower in Asian women, with 11 (35%) Asian women declining this screening compared with two (6%) White women.
- The standard of neonatal care provision was similar for both Asian and White babies.

- Medication for lactation suppression was more likely to be offered to and accepted by Asian women (68%) than White women (46%).
- Post-mortem was carried out for 18% of Asian and 51% of White stillbirths and neonatal deaths.
- Placental histology was carried out for the vast majority of Asian (91%) and White (85%) stillbirths and neonatal deaths.
- The quality of maternal and pregnancy information provided for post-mortem was similar for Asian and White babies.
- Following stillbirth, follow-up letters were more likely to be addressed to the GP (with a copy for the parents) for Asian parents (60%) than White parents (25%).

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 Asian women for gestational diabetes mellitus (GDM) was inconsistent and did not follow guidance (NICE, SIGN). Of the 23 births after 28 weeks in this group of women, five (22%) of the Asian women eligible were not offered an oral glucose tolerance test (OGTT) in line with national guidance. Of the 29 White women who gave birth after 28 weeks, only one of the women eligible (3%) was not offered an OGTT.

There was a failure to measure carbon monoxide levels at booking for 11 (34%) Asian women compared with 9 (26%) White women.

National guidance indicates that Asian women require a high dose of Vitamin D (25 micrograms or 1000 International Units per day). There was a failure to recognise this requirement for almost all of the 31 eligible Asian women in this enquiry, with 28 women (90%) not receiving this increased dose. None of the four White women meeting the criteria received high dose vitamin D. Whilst the proportion of women affected by lack of compliance with this guidance is higher for White women, the impact on Asian women is significantly greater as all Asian women receiving antenatal care are eligible for the high dose of Vitamin D.

The uptake of antenatal screening for chromosomal conditions was lower in Asian women. Where Asian women were offered this screening, 11 (35%) Asian women declined compared with two (6%) White women. Panel members were unable to determine from the notes whether adequate information had been provided, adequately translated (where necessary) and understood by these women to enable them to make an 'informed choice'.

5.4. Labour and birth

There were similar levels of major or significant sub-optimal care identified for Asian and White mothers during labour and birth. Panels did not identify any specific differences between the quality of care provided for Asian mothers and that provided for White mothers.

5.5. Neonatal care

Good neonatal practice was noted for 15 of the pregnancies of Asian women and 13 of the pregnancies of White women. This includes women whose babies were stillborn, but who received input from the neonatal team as part of their antenatal care. The aspects of good care noted were very similar in both type and number, particularly with regard to building trust with families, multidisciplinary team discussion and planning, having senior staff available at delivery and undertaking joint obstetric/neonatal follow-up.

Of the babies who died in the neonatal period, suboptimal neonatal care was identified in seven of the 14 babies born to Asian women (range 1 to 15 issues per baby) compared with four of the eight babies born to White women (range 2 to 12 issues per baby). Whilst the types of suboptimal care noted were very similar between the two groups, there were relatively more instances in babies born to White women. The exception to this was regarding communication issues (including language) which were noted more commonly for the Asian women.

The suboptimal neonatal care identified mirrors that highlighted in previous confidential enquiries and other independent reviews of perinatal services. By far the commonest issue identified was around clinical management, particularly resuscitation and early thermal care, but also included delays in commencing antibiotic treatment for suspected sepsis. This was compounded in several cases 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 case or expediting specialist referral was felt to have contributed significantly to the outcome in several cases. There were numerous instances of poor documentation (including prescribing).

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 to Asian women. 23 Asian women accepted Cabergoline, four declined and eight were not offered. Whereas, 17 White women accepted Cabergoline, one declined and 18 were not offered. While bereavement photographs of their baby were offered to most women (they were not offered to one White and one Asian woman), it was more likely to be declined by the Asian women (8 versus zero). In five of the eight Asian women who declined photographs of their baby, the baby had been diagnosed with a congenital anomaly.

Bereavement care within the hospital from the midwifery and obstetric teams was given for most parents (31 Asian, 32 White), but some women whose baby died after birth may not have had in-hospital care from the maternity team. Follow up care in the community was less good, with only 19 of the Asian women and 23 of the White women seen by a community midwife at least once (the number seen 3 or more times was similar). The quality of community care was reported to be "poor" for 10 Asian parents and seven White (this difference was primarily accounted for by those who had suffered a neonatal death)

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 this occurred as well as information relevant to the clinical management of any subsequent pregnancies. Of the deaths reviewed, post mortem was carried out for only six (18%) of Asian stillbirths and neonatal deaths, of which three were coroner's post mortems and two post mortems were limited (external review, MRI, X-ray etc). All three coroners post mortems were carried out for Asian Pakistani babies and the remaining three were carried out for Asian Other babies indicating that none of the parents of the babies, where the mother's ethnicity was Asian Indian, Pakistani or Bangladeshi, gave their consent for either a full or limited post mortem. This compares to 18 (51%) post mortems for the White stillbirths and neonatal deaths (including 3 coroner's PMs). Placental histology was carried out for vast majority of Asian (91%) and White (85%) stillbirths and neonatal deaths. For two White stillborn babies placental histology was not carried out. Of the six post mortems carried out for Asian babies, only two were carried out by a specialist perinatal/paediatric pathologist.

Table 10: Pathological examination

Type of pathological examination	Asian women N=34	Asian women %	White women N=35	White women %
Post-mortem	6	18	18	51
Full	1	3	15	43
Limited	2	6	0	0
Coroner's/Procurator Fiscal's	3	9	3	9
None	28	82	17	49
Placental histology	32	91	30	86
Carried out by non-perinatal/paediatric pathologist	4	13	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 two of the three (66%) post-mortem reports available to the enquiry and 16 out of 30 (52%) placental histology reports for Asian 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 11: Quality of post-mortem and placental histology reports

Grading of post-mortem report [note 1]	Asian women n=3	Asian women %	White women n=17	White women %
Excellent	1	33	6	35
Good	1	33	6	35
Satisfactory	1	33	3	18
Poor	0	0	2	12
Grading of placental histology report [note 2]	Asian women n=30	Asian women %	White women n=29	White women %
Excellent	10	33	3	10
Good	6	19	13	45
Satisfactory	12	39	7	24
Poor	2	7	6	21

Note 1: Four post-mortem reports (three Asian, one White) were unavailable for review.
Note 2: One White and two Asian placental histology reports were 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 33% of Asian post-mortems and for no White post-mortems. The most commonly missing maternal items were maternal BMI (missing for 33% Asian and 77% White) and family history (missing for 33% Asian and 71% White). High proportions of pregnancy items were missing across both ethnicities and for the full range of required information, e.g. estimated due date, 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. Translations should not be carried out by family members. 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. The GP can be written to separately, or copied into the parents' letter. This was worst for the Asian parents following stillbirth, where 60% of letters were addressed to the GP (compared with 25% for White parents following stillbirth). 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.

Future pregnancy plans and/or contraception were not discussed with 13 Asian women and 12 White women at any point during their postnatal care.

Fourteen Asian and 10 White women did not have a follow-up appointment. This includes one Asian woman who had an appointment booked for 20 weeks after her baby's death, but this was cancelled and postponed until June 2020. For parents where follow-up appointments did not happen, letters were either not written or were very medical in their nature.

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 Asian 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, 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 69 babies in this enquiry were reviewed locally using the PMRT. The deaths of three babies, whose mothers were of White ethnicity, 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. This is also reflected in the overall lower proportion of Asian compared with White parents who asked questions and/or expressed concerns about their care.
- 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 more common for Asian mothers and babies (38%) than White mothers and babies (22%).
- 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

Not all parents had been informed that a local review of care would take place and this was the same for the two different ethnic groups. Those who had been informed were 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; there were more parents of babies of Asian than White ethnicity in this group. Except for one set of parents who sent positive comments about their care, all parents with an identified language barrier, regardless of ethnicity, did not indicate if they had questions or concerns. About a third of parents of babies of White ethnicity asked questions and/or expressed concerns about their care whereas it was about a sixth of parents of babies of Asian ethnicity. The types of questions/concerns were qualitatively more detailed from the parents of babies of White ethnicity.

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 three of the 66 reviews were highlighted as being a "good" quality review with 21 of the remainder were assessed as being of "poor" quality, not carried out by an adequate multidisciplinary team and/or failed to address parents' questions or concerns.

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*;
- follow national guidelines for induction of labour for high risk pregnancies;
- 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 a glucose tolerance test (GTT) had not been offered a GTT;
- identify that there was an issue with substance misuse;
- appropriately assess the mother's social circumstances.

The was a higher number of reviews identified as "poor" quality for the babies of White than Asian ethnicity, and the range of elements identified as poor quality was wider as a consequence of there being more elements that were of poorer quality.

More mothers of babies of Asian rather than White ethnicity had an identified language barrier. 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 language for half of the women with an identified language barrier.

The confidential enquiry panels identified two specific reviews where the parents asked pertinent questions about critical elements of their care which were also identified by the confidential enquiry panel members as being critical to the outcome for the baby. The local review groups neither identified these critical issues nor addressed the parents' questions. Had they done so, the confidential enquiry panel members felt the PMRT conclusions and subsequent actions to improve future care would have been different.

Vignette 8: The importance of listening and responding to parents' questions and concerns about care

A young White mother was having her second baby. She had a BMI of 41 and complex social problems, and was referred for multi-agency and smoking cessation support. She missed several antenatal appointments. Her baby was on the 5th centile for growth, the rate of growth was decreasing and induction of labour was planned for 38 weeks. A growth scan at 37+2 identified that the baby had died. Following the birth she did not receive bereavement support or ongoing follow-up.

The parents questioned whether the baby should have been delivered earlier when the baby's growth rate started to decrease. The local PMRT review which was carried out by several midwives and a paediatrician did not address the parents' question and failed to review this aspect of care. The only issue with care identified was that labour was not monitored on a partogram. The care was graded as A: No issues with care identified. At follow-up an incorrect cause of death was conveyed to the parents and future pregnancy planning did not include addressing her weight and other lifestyle issue.

The confidential enquiry panel concluded that the local PMRT review was inadequate, there were no obstetricians involved and the local review group did not identify the main issue with care that may have affected the outcome for the baby: a failure to offer induction at 37 weeks' gestation for a growth restricted baby whose rate of growth has decreased, as per national guidance. Had the local review group addressed the parents' question and assessed their care against national guidance they would have identified that there was an issue with care that may (grade C) or was likely (grade D) to have affected the outcome for the baby. Furthermore, had the local review group not misinterpreted the post-mortem findings, more appropriate future pregnancy planning could have been provided.

6.6. Multidisciplinary review groups

Thirteen reviews (38%) of the care of babies of Asian ethnicity and seven reviews (22%) 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 nine of the reviews of babies of Asian ethnicity 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;
- despite the particular circumstances a wider group of professionals with specific and essential expertise were not present at the review.

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 60% of the PMRT reviews the pregnancy, labour and birth care was graded A, as having no issues with care identified; 29% were graded as B, issues with care which would have made no difference to the outcome for the baby; and 11% were graded as C/D where issues with care were identified with may or were likely to have made a difference to the outcome. Thus, overall 40% of local 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 neonatal care was also not different by ethnicity.

The holistic grading of care agreed by the confidential enquiry panels differed from that of the PMRT in many instances. When reviewed by the enquiry panels, the care of the baby was graded as (1) good with no improvements identified for 24% of babies of Asian 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 50% of Asian babies and 29% of White babies; and as (3) improvements in care which may have made a difference to the outcome for 26% and 49% of babies respectively. Overall, improvements in care were identified in 76% of the deaths of Asian babies and 78% of the deaths of White babies.

6.8. Summary of findings and lessons learned

The main difference between the local reviews of the two groups of babies was the quality of the reviews where 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; there were more language problems for the parents of Asian babies, this was not always identified as an issue with care during the local review; language barriers appeared to impact on parents' capacity to ask questions or raise concerns with their care; and local review panels were less likely to be properly constituted for the review of Asian babies although more of the local panels for these reviews had an external professional member present.

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 for reviews of babies of Asian ethnicity and 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 60% and with improvements in care which may or may not have made a difference to the outcome identified for 40%. In contrast, the grading by the confidential enquiry panels had a greater proportion where improvements were identified. There was a difference by ethnicity with a greater proportion of improvements identified in the care which would not have made a difference to the outcome of babies of Asian ethnicity (50%) compared with babies of White ethnicity (29%). Conversely the proportions of improvements identified which may have made a differences to the outcome were 26% and 49% respectively. This difference is most likely due the babies of Asian ethnicity being more likely to have a lethal or high risk congenital anomaly. 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.