Comparing the care of Black and White women whose babies died



Lay Summary

Around 700,000 babies are born every year in the UK, and around 3,500 of these babies die before, during or shortly after birth. The <u>most recent figures</u> show that even though the overall proportion of babies dying has reduced over the past 5 years, there are still big differences in the proportion of babies from different ethnic groups who are dying. Among all the ethnic groups, Black babies now have the highest rate of stillbirths and deaths in the first 28 days after birth.

This enquiry looked at the pregnancies of 36 Black women and 35 White women in 2019, where the baby was stillborn or died within 28 days of birth. The aim was to review the quality of care, as it was recorded in the medical notes, and to find out whether different care may have made a difference for the baby and the mother. The care the babies and their mothers received was compared with care outlined by national guidelines for best practice, by a group of clinical experts. The enquiry also compared the care given to Black women and White women to see if it was different.

The care reviewed included when mothers were pregnant; care during labour and birth; care for their baby once born; postnatal and bereavement care after the baby died; and any tests or investigations that took place to understand what happened and where improvements in future care are needed.

The clinical experts looked at whether the care women and babies received may have contributed to the babies' deaths. They also looked at the quality of emotional and psychological help and support provided for women, both during pregnancy and when their baby died. This included the offer of a post-mortem and the quality of local hospital death reviews to understand why the baby died.

The enquiry could only look at what was written in the medical notes. This means that the experts couldn't take into account things that weren't always written down, such as how staff spoke to women or how they behaved. The experts also couldn't get feedback from the families involved, because the names of the families were kept anonymous. To make sure that the voices of bereaved Black parents are heard alongside learning about clinical care, the charity Sands have conducted a "Listening Project". You can read about this on <u>their website</u>.

Key Findings

For both groups of women, high quality care was found in a minority of the baby deaths which were reviewed. Many deaths may have been prevented with better care.

- » In around 1 in 2 baby deaths, the care was assessed as poor. If care had been better it may have prevented the baby from dying.
- » For around 3 in 5 mothers, care after their baby died was assessed as poor. If it had been better, it may have meant bereaved mothers were likely to have been better supported in their physical and emotional health.
- » In both groups, the care was assessed as good in only around 1 in 5 of the deaths reviewed.

Care of vulnerable women

- » Women's ethnicity, nationality and citizenship status was not always correctly recorded in the notes. This may have made it harder for staff to offer the personalised care the woman needed.
- » When a woman's first language wasn't English and she needed an interpreter, this wasn't always provided. Sometimes, family members were used as interpreters instead of professionals. This meant the woman might not have received the information she needed or been able to talk about some things in private.
- » Some women faced challenges in their personal lives which were not always recognised or taken into account when planning their care. This meant that some women didn't receive the additional support they needed. These challenges were more common for White women.
- » A small number of Black women found it difficult to get certain types of care or advice, even if it was offered to them. This meant that they didn't always take their prescribed medication, left the hospital against medical advice, or missed appointments with specialists.

Care during pregnancy (antenatal care)

» Antenatal care was assessed as good for 1 in 5 Black women and 1 in 3 White women.

Care during pregnancy (antenatal care) - continued

- » Blood tests to check for a condition that causes high blood sugar, called gestational diabetes, were not offered to 1 in 3 Black women. Almost all the White women who should have been tested were offered a test.
- » All the Black women should have been offered a high dose of Vitamin D to take during their pregnancy, but none of them were.

Care during labour and birth (intrapartum care)

- » A partogram, which records important information about the mother and baby during labour, wasn't completed for 2 in 3 Black women and 1 in 3 White women, even when there was enough time.
- » When women asked for pain relief during labour, it was not given within 15 minutes for around 1 in 3 women. This was the same for both groups.

Care of the baby after birth (neonatal care)

» For babies who died within 28 days of birth, care of the baby after birth was assessed as poor for 1 in 2 babies. The experts didn't identify any specific differences between the quality of care received by Black babies and White babies.

Care after birth and death (postnatal and bereavement care)

- » Medication to stop breast milk was more likely to be offered to, and accepted by Black women than White women.
- » The quality of bereavement care was good for around 1 in 2 women. This was the same for both groups.
- » Most parents were offered a follow-up appointment to discuss what happened and how they were coping.
- » After the meeting, most parents received a letter summarising what they talked about, but this wasn't always directly addressed to them. Sometimes the letter was addressed to their GP instead. Black parents were less likely to receive a follow-up letter directly addressed to them than White parents. In both groups, 1 in 3 parents didn't receive a letter at all.

Tests and investigations to find out what happened when babies died (post-mortem and hospital review)

- » Around 1 in 4 post-mortem and placental examination reports didn't contain information to connect what happened during the pregnancy and what the investigations found.
- » Almost all deaths were reviewed by the hospital using the Perinatal Mortality Review Tool (PMRT). The hospital reviews were more positive than the conclusions reached by the confidential enquiry panels, but this wasn't affected by the mother's ethnicity.
- » Many reviews were carried out by only one doctor or midwife instead of a group, or by a small group without enough of the right specialists.
- » Where deaths were reviewed, parents were given the opportunity to ask questions and say how they felt about the care they received. Most parents said they didn't have any questions. Parents whose first language wasn't English didn't ask any questions.



About MBRRACE-UK

MBRRACE-UK is a team of researchers, clinicians and representatives of parent groups and charities. Every year we collect and analyse data about baby deaths from UK hospitals. We then use this data to identify the different groups of women and babies who are at risk of stillbirth and neonatal death. Every two years an independent group of experts choose a group of women and babies for MBRRACE-UK to look at in more detail. The medical notes for the women and babies are reviewed by clinical experts, in a process called a confidential enquiry. The findings from each enquiry are then used to write recommendations for improving the care of women, babies, and their families.

You can learn more about MBRRACE-UK on our website.

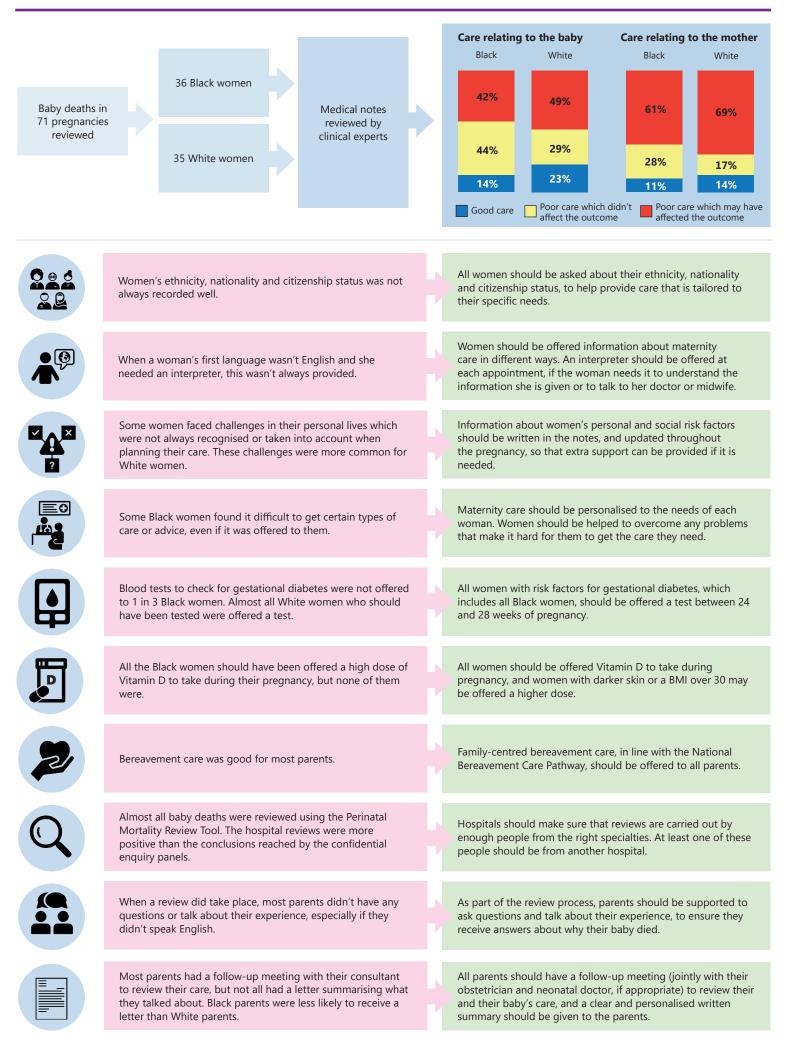
Lay summary written by MBRRACE-UK and Jenny Douglas (Open University), Sandra Igwe (The Motherhood Group), Nana-Adwoa Mbeutcha (Black Mums Upfront), Benash Nazmeen (University of Bradford), Selena Palmer (University of Leicester), Janet Scott (Sands). Design and Iayout by Ian Gallimore.

Icons: <u>Care</u> by James, <u>Diabetes</u> by Pablo Rozenberg, <u>Discussion</u> by Vectorstall, <u>Diversity</u> by Iconathon, <u>Language</u> by Adrien Coquet, <u>Letter</u> by Prasad, <u>Magnifying Glass</u> by Milinda Courey, <u>Pregnant Woman</u> by Diego Naive, <u>Risk Factors</u> by Nur Lita, <u>Urgent Medical Care</u> by Bold Yellow, <u>Vitamin</u> by Jauhari, from <u>nounproject.com</u>.

 $\ensuremath{\mathbb{C}}$ 2023 The Infant Mortality and Morbidity Studies, University of Leicester.

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Messages for women and families



What you should expect from your care – a checklist

- ✓ At your first appointment, you should be given a <u>list of the appointments</u> and scans that you should have during pregnancy. The importance of each should be explained to you.
- \checkmark You should be offered an interpreter at each appointment, if you need it.
- ✓ You should be asked about your ethnicity, nationality and citizenship status so this is correct in your notes.
- \checkmark You should be asked about your safety at home and offered help if you need it.
- \checkmark You should be asked about how you feel and be supported to say what you need.
- \checkmark You should be offered Vitamin D to take throughout your pregnancy.
- ✓ If you are Black or Asian, you should be offered a blood test to check for a condition that causes high blood sugar, called gestational diabetes.
- ✓ If you have had gestational diabetes before, you should be offered a blood test after your first appointment.
- \checkmark If your baby dies, you and your family should be offered bereavement care.
- ✓ If your baby dies, you and your partner should be given clear information about the different types of <u>post-mortem</u> and <u>how it might help you to understand why your baby died</u>.
- ✓ If your baby dies, a <u>hospital review</u> of what happened should take place, using the Perinatal Mortality Review Tool. This is a review of whether your care was right for you and your baby. You should be told that a review is going to take place, and asked about your experience of your care and if you have any questions.
- ✓ If your baby dies, you should be offered a meeting with a doctor to talk about what happened and your future care. Afterwards, you should be sent a letter which says what you talked about, and answers any questions you have.

Further information and support

- » The NHS has a web page with information about trying for a baby, pregnancy, labour and birth.
- » If you have a concern about your care, raise it with the team looking after you.
- » Every hospital has a Patient Advice and Liaison Service (PALS), who can help you if you do not feel you are being listened to.
- » If you want independent advice about your care, these organisations have helplines and support teams you can contact and information and resources you can use:

The Motherhood Group supports Black mothers with access to safe spaces.

Tommy's provides expert, midwife-led advice for parents before, during and after pregnancy.

Bliss supports families whose baby is born sick or too soon.

Sands is a charity working to save babies' lives and support bereaved families.











