

Review of neonatal assessment and practice in Black, Asian, and minority ethnic newborns

Executive Summary

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Ethnic inequalities in maternal and neonatal healthcare provision are increasingly being recognised across the UK (Draper at al., 2022; Knight et al 2022). There are particular concerns around perinatal practices including Apgar scores and assessment of cyanosis and jaundice, all of which have been developed based on White European babies and normalised regardless of their applicability to diverse populations and neonates with varying skin tones (Kapadia et al., 2022).

This report presents the findings and recommendations from a review of neonatal assessments which, because of their focus on skin colour, have the potential to disadvantage babies with darker skin tones. The research involved a triangulation of approaches, including systematic reviews and qualitative research, to gather feedback and experiences from healthcare professionals and parents from Black, Asian, and minority ethnic groups. The study investigated three main areas of neonatal assessment, namely Apgar score, cyanosis, and jaundice. Additionally, the report examined existing policies relating to skin colour and neonatal assessment, with a focus on these same areas. This work has been conducted by academics and clinicians from Sheffield Hallam University, Bradford Teaching Hospitals and Bradford Institute of Health Research, Hull York Medical School, and the Royal College of Paediatrics and Child Health, alongside maternity and neonatal service user representatives.

Specific objectives of the review included:

- Reviewing the use of the Apgar score, with particular focus on the appearance component, as well as the more general detection of cyanosis in Black, Asian, and minority ethnic neonates within the relevant literature and among stakeholders.
- Reviewing the identification of jaundice in Black, Asian, and minority ethnic neonates within the relevant literature and among stakeholders.
- Examining the wider use of terminology used in policy and practice to ensure Black, Asian, and minority ethnic neonates receive equitable care and treatment.
- A broader analysis of potential inequalities for Black, Asian, and minority ethnic neonates within the UK.

A mixed methods approach was adopted to achieve the above objectives, comprising a desktop review of policy documents and systematic reviews, and stakeholder interviews. The data collection was carried out concurrently and results were combined with an equal weighting in a complementary paradigm.

Summary findings and recommendations are presented based on approach and topic area below.

Systematic review of healthcare professionals' experiences of providing care for Black or Asian or minority ethnic neonates in relation to neonatal assessment (Apgar, Cyanosis and Jaundice)

Out of 217 studies which were screened at full text, 56 studies were included as they reported comparative results between different ethnic minority backgrounds for the topics of interest. Six studies related to Apgar scores, three considered the detection of cyanosis, with the remainder considering the detection of jaundice. All but four of the studies were undertaken in developed countries. The impact of ethnicity and race in Apgar scoring remains unclear as studies also highlighted inconsistent scoring of the Apgar, with Black infants more likely to receive lower scores.

Detection of cyanosis from skin colour was noted to lead to many false positives and false negatives. Within one small study, the lips were considered the most reliable places to assess cyanosis across different ethnicities. A further study suggested that tongue colour being pink within the first ten minutes of life suggested that a neonate had an oxygen saturation above 70% regardless of ethnicity. Pulse oximetry is more reliable than observation of the skin, although one study has found occult hypoxemia, where pulse oximetry levels were 90% or more when arterial oxygen saturation was <85%, was slightly more common in Black infants (9.2%) compared to White infants (7.7%). Further exploration of the small but potentially clinically significant differences in arterial oxygen saturation compared to pulse oximetry in neonates from diverse race and ethnicity backgrounds is warranted.

Transcutaneous bilirubin (TCB) measurement has been found to be a more accurate method of detecting jaundice than visual assessment alone. However, when it comes to considering ethnicity, there is no consistent pattern regarding the correlation between TCB and serum bilirubin (SBr) or mean bias (TCB reading – SBr level). Some studies have found higher values in individuals with dark skin tones or from ethnic minority backgrounds, while other studies found lower values or no difference.

In terms of the utility of bilirubinometers, outstanding discrimination was seen across all ethnic and skin tone subgroups and across a range of SBr cut-offs,

except for the Bilimed brand. Screening full-term neonates with transcutaneous bilirubinometers may result in more blood testing needed in neonates of 'non-White' ethnicity or darker skin tones than in neonates of White or light skin.

Additionally, five of the seven studies that statistically assessed the limits of agreement around the mean bias (TCB reading -SBr level) found that variability was increased with increased pigmentation, with most of these TCB measurements noted to have been taken from the forehead. However, none of the included studies found the mean difference between TCB and SBr to be underestimated by more than 40µmol/l in neonates of any ethnicity.

Two studies considered healthcare professionals training. In one study, midwives and student midwives reported lack of education in clinical assessment of Black, Asian, and minority ethnic mothers and babies, with the study particularly focussing on assessment of the Apgar score. After the training, 96% of midwives felt the Apgar score was not the most appropriate way to assess all babies at birth due to the description of colour within it. The second study found maternity care assistants' knowledge and self-perceived confidence in detecting jaundice was not associated with actual ability to correctly estimate SBr levels from visual assessment.

Systematic review of the experiences of parents or carers seeking or receiving care for Black, Asian and ethnic minority neonates in relation to neonatal assessments (Cyanosis and Jaundice)

Out of 110 studies which were screened at full text, nine studies were included in this review. No studies conducted in high income countries considered the views of Black, Asian or minority ethnic parents or carers of the Apgar score or how parents from ethnic minority backgrounds may use skin colour to detect whether their baby is getting enough oxygen or subsequently seeking care. Just two studies reported incidences where mothers talked about their baby's struggles to breathe as part of a wider study of care experiences.

Only seven studies considered parents from Black or minority ethnic backgrounds experiences of neonatal jaundice, of which only three studies considered the identification of jaundice. These three studies reported jaundice to be inadequately identified in their infant by healthcare professionals with concerns dismissed by a healthcare professional in one study and the woman not wanting to make a fuss by raising her concerns in another study. The other studies focussed on parents' inadequate understanding of jaundice when there was a language barrier, the anxiety they felt after a jaundice diagnosis, as well as how well they remembered the jaundice diagnosis over the following months.

Policy review to examine current policies and guidance in relation to their consideration of Black, Asian and ethnic minority neonates in common assessments (Apgar scoring, cyanosis and jaundice)

There were 18 policy and guidelines reports and one training resource in this review. Of the 18 policy documents, nine focused on general care of neonates, six exclusively detailed the assessment of cyanosis or hypoxia, one neonatal assessment using the Apgar score, and two exclusively focussed on the assessment of jaundice. Of the 18 policies, 15 were UK polices and three were international policies from WHO.

UK policy was assessed to understand whether ethnicity and race were appropriately considered in policy formulation regarding skin colour and neonatal examinations. The review showed that the impact of ethnicity was poorly considered during policy formulation and the development of most guidelines and training. Multiple policies referred to terms such as "pink" "blue" "pale" or "pallor" in reference to neonatal skin, without detailing how these skin colour descriptors may appear in ethnic minority neonates. These results further perpetuate the inequalities faced by those from Black, Asian, and ethnic minority backgrounds, by means of improper assessment or potential late diagnosis.

Stakeholder interviews

A focussed ethnography approach was used for stakeholder engagement, including semi-structured interviews of healthcare professionals (HCPs) and parents or carers. A systematic inductive approach was undertaken to analyse qualitative data using NVivo.

A total of 33 HCPs were interviewed, including thirteen midwives, eight health visitors, four paediatricians, three obstetricians, three neonatologists, and two neonatal nurses. Eleven HCP participants described themselves as Black, three as mixed ethnicity, two as Asian, and the remainder as White.

In total, 24 parents were interviewed of whom fifteen participants were Black (Black African n=12, Black Caribbean n=1, other Black background n=2), three were Asian (Indian background n=2, any other Asian background n=1), three were mixed ethnicity (Black Caribbean and White British n=2, African-Asian n=1) and two participants were from other ethnic groups, both being Arab. One mother was White and had a child of mixed ethnicity.

The interview results yielded a multitude of varied themes, some overlapping for the three conditions of focus: Apgar, cyanosis and jaundice. In-depth

discussions were had about changing pigmentation at birth, relevance of different skin colour descriptors (blue, pink, pale), suggestions for alternative practices, challenges in detection of these conditions, training needs, better listening skills, and improved communication between HCPs and parents.

There was a general consensus from HCPs and parents that the term "pink all over" in Apgar scoring is derived from observing White babies, and its relevance to babies from Black, Asian, and minority ethnic backgrounds was generally questioned. It was suggested that, due to the implicit bias within the Apgar score, continued use may be considered inherently racist in a multi-cultural society where infants hold diverse phenotypes.

However, for some, the question seemed to be where to look for "pink" or for "blue" colour as part of a whole range of other indicators for the health and wellbeing of the babies. Around the lips or the mouth mucosa were frequently cited by parents and HCPs to be an appropriate place for assessing cyanosis and for the appearance component of the Apgar score in all ethnicities. However, difficulties in detecting cyanosis in all infants, and particularly those from ethnic minority backgrounds, was noted.

Assessing the sclera and gums, rather than the skin, for jaundice were reported by HCPs to enable better detection in Black and minority ethnic neonates. However, visual assessment was noted to be poor with HCPs having a low threshold for testing TCB or SBr if any signs of jaundice were detected.

Some stakeholders felt there was a need for more appropriate training and educational materials for consideration of skin colour when undertaking neonatal assessments, as well as exposure to babies with variations in skin tone. To facilitate equitable maternity and neonatal care for all, some stakeholders suggested creating opportunities for exposure to multi-ethnic and racially diverse communities for all HCPs and establishing a databank of pictures from diverse communities and babies with various conditions.

The impact of ethnicity and race on care

Although the overall focus of this review was on neonatal assessments, challenges around the quality of care could not be ignored within the context of race and ethnicity. The systematic review of the experiences of parents or carers therefore also highlighted potential barriers (and facilitators) to accessing care for these communities. Similarly, within the stakeholder interviews, parents and healthcare professionals were asked about challenges or barriers to accessing or receiving care and any areas of good practice. These findings were then analysed, with several themes emerging.

The first theme identified was the communication barrier, where women faced problems in getting information from HCPs due to language differences or inadequate translation. Another issue was women being silenced within the system, where they felt dismissed, ignored, or belittled by HCPs. Fear of raising concerns was another reason why women remained silent, as they worried about being labelled as "difficult" or "too much trouble".

The literature and interviews reviewed also revealed discrimination and racism in healthcare. Three specific areas of discrimination were identified, including stereotypes, lack of cultural competence, and inadequate care. In both the literature and in the interviews, women reported assumptions about their education and lifestyle and felt HCPs labelled Black, Asian, and minority ethnic women as "aggressive" or "difficult". Parents and HCPs felt HCPs sometimes made unfounded racial assumptions about Black and minority ethnic women's bodies and lacked cultural competence, resulting in over-medicalisation of childbirth and inadequate pain management. HCPs also overlooked potential difficulties due to women's skin tone and failed to offer culturally tailored care. While few parents within the interviews reported feeling that their culture was not understood, the need for HCPs to understand a woman's culture to better support her was recognised.

Inadequate care towards Black, Asian, and minority ethnic parents was reported in multiple studies and in the interviews. Racist microaggressions, including mispronouncing names and discriminatory comments, were reported in interviews with parents and within the studies included in the review. Lack of dignity and respect, neglectful care, and being left in vulnerable states were also commonly reported. Some mothers even engaged lawyers due to traumatic experiences and obstetric violence. HCPs noted that discrimination was present in complaints received from parents.

Systemic and organisational factors were also identified. These included difficulties around accessing appointments due to lack of knowledge about who and when to contact and a lack of flexibility within the system. Staffing was also raised as an issue, with workload pressures and lack of training thought to make discrimination more likely as overworked staff rely upon their biases more. Charging some migrants for care depending on status was also seen as an organisational barrier.

Social isolation, socio-economic status, and racism in society were identified as contextual issues impacting maternity care, as reported by both parents and HCPs. These issues included a lack of support network, inadequate housing, poor nutrition, mental health issues, and the racism they faced in general in society. There are inequalities in health outcomes, particularly for those from ethnic minority backgrounds, and racism affects parents' choices and feelings about maternity care. Some parents changed their birth preferences due to concerns over discrimination and the additional risk of maternal and neonatal mortality for Black, Asian, and minority ethnic families.

Overall, the above highlights the need for HCPs to be more culturally competent and provide personalised, culturally safe, care, as well as the need for more support for parents from seldom-heard communities. Addressing racism and discrimination in healthcare, society, and decolonising the curriculum, practice, and policy is crucial for improving maternal and neonatal health outcomes, ensuring that all parents receive respectful and dignified care.

Recommendations for practice

- 1. Given poor visual detection of jaundice and cyanosis, particularly in Black and darker skin toned neonates, the following recommendations are made:
 - Jaundice: Exploration of wider availability and use of bilirubinometers is recommended to decrease health inequalities and ensure safe care for all. Collaboration with organisations such as BAPM, RCM and RCPCH, RCOG, iHV, CQC and other key stakeholders is recommended.
 - Cyanosis: Healthcare organisations should strongly consider use of pulse oximetry screening if there is any indication of concern over oxygenation.
 For this reason, the UK National Screening Committee should also strongly consider including routine pulse oximetry screening as a requirement within NIPE (the Newborn and Infant Physical Examination) to mitigate the health disadvantages experienced by those with darker skin tones.
- 2. NHS England to create a national data bank of open access images of Black, Asian and ethnic minority neonates to incorporate into training and education of HCPs and healthcare students, as well as to aid diagnosis in practice. These images should also be available for use in accessible resources for families. These should incorporate images of healthy neonates, as well as specific conditions such as cyanosis and jaundice, and other conditions suggested by participants, including skin rashes and sepsis. Hard copies and digital sources should be provided, including on platforms such as the online NHS Health A-Z pages. These images should be made available and used by all NHS provider organisations and the NHS should create an opportunity for people to upload pictures and share experiences of conditions in different skin tones.
- 3. There is an urgent need for regular education and training for healthcare professionals and healthcare students on undertaking clinical assessments on neonates from Black, Asian, or minority ethnic backgrounds, including within the yearly updates on neonatal resuscitation. Better education for families is also required. All training requires process evaluation to ensure effectiveness. Further action on training and education should be taken as follows:

- In order to remind learners of the challenges that varying skin tones may introduce when assessing clinical signs, it is important for resuscitation dolls in all Higher Education Institutions and NHS Trusts to include babies with Black or dark skin.
- Professional associations (including BAPM, iHV, NNA, RCOG, RCPCH, RCM, RCN) and regulatory bodies (NMC and GMC) should identify training requirements to ensure that those they represent are fully competent in assessments that include skin colour for Black, Asian, and ethnic minority neonates. In addition, they should ensure all HCPs and students are made aware that some ethnicities are at higher risk of neonatal jaundice.
- All healthcare students should have access to an actual or simulated placement to increase students' awareness, knowledge, and confidence in assessing Black, Asian, and minority ethnic neonates prior to qualification.
- An urgent review and update of written and digital materials provided to parents is required. These should be co-developed with parents or carers from diverse ethnicities. A particular focus should be around jaundice and detecting a deteriorating infant to ensure accessibility and relevance of pictures and information to those from Black, Asian, and minority ethnic backgrounds.
- Both community and hospital staff should receive training on anti-racist practice, alongside culturally safe, compassionate care, with good listening skills to meet the needs of our diverse, multi-ethnic society and to reduce current health inequalities.

Recommendations for policy

- 4. Guidelines that refer to neonatal assessment by skin colour should be immediately reviewed and updated to highlight the impact of race and ethnicity (BAPM, HEE, iHV, NICE, NNA, OHID, RCM, RCN, RCOG, RCPCH, Resuscitation Council, WHO). This should include guidelines around general care of the newborn, as well as specifically for jaundice, cyanosis, and Apgar scoring. Further action should be taken in the following areas:
 - Attention should be drawn to any potential differences in assessment techniques for Black, Asian, and ethnic minority neonates.
 - Guidelines or educational materials that currently refer to the terms pink, blue, or 'normal' colour need to detail how this would be assessed more objectively in Black and darker skinned neonates.

- All guidance needs to highlight the limitations of visual assessment of the skin, particularly in those from ethnic minority backgrounds. A comprehensive assessment of other areas including sclerae and gums for jaundice and mouth mucosa for cyanosis is recommended. If jaundice is suspected, additional TCB or SBr should be undertaken.
- When screening tools such as pulse oximeters or bilirubinometers are advised, rather than clinical visual inspection, particular attention should be given to any differences in reliability or accuracy for neonates with different skin pigmentation. When advising the use of a bilirubinometer, a minimum threshold below the treatment line when a confirmatory SBr test is required needs to be urgently established to ensure appropriate detection of jaundice regardless of ethnicity.
- All guidelines should contain or signpost to images and good descriptors of skin assessments in those of all skin tones to support recognition of conditions in those who do not regularly have exposure to Black, Asian, and minority ethnic neonates.

Recommendations for research

Regarding the Apgar score

- 5. The wording 'pink all over' was not considered appropriate within the UK by the majority of HCPs and parents, including for White neonates. Further exploration is required, including:
 - Determination of inter-rater reliability between HCPs when undertaking the Apgar score in Black, Asian, and minority ethnic neonates. In particular, a better understanding of how HCPs determine the Apgar score in darker skinned babies is required, with specific attention to the terminology of 'pink all over' and the location of pink areas.
 - A systematic review is required of alternative scores or assessments such as the Neonatal Resuscitation and Adaptation Score and Expanded Apgar, compared to the Apgar score including their reliability and validity in Black, Asian, and minority ethnic neonates.

Regarding jaundice

Research required around jaundice includes:

- 6. In depth case study/root cause analysis of severe cases of jaundice, including those admitted to neonatal units for intensive phototherapy, requiring an exchange transfusion, or with resultant kernicterus. Clear consideration of confounding factors is required, as well as timing and content of contact with HCPs. This could inform better identification, prevention, and timely management of severe jaundice.
- 7. A better understanding of what level jaundice is by the time it reaches the eyes or gums is required given concerns voiced by HCPs that the areas we currently look at to identify jaundice in Black or darker skinned neonates actually identify jaundice at an advanced stage.
- 8. Determining inter-rater variability in assessing jaundice to evaluate the impact of skin tone and race on HCP ability to detect jaundice.
- 9. Current guidelines within the UK vary in their recommendations for when a TCB reading should be followed up by a SBr. Further investigation and confirmation of a more accurate and consistent threshold for adequate identification of infants, particularly for those of varied race and ethnicities is required.
- 10. Given the wide availability of mobile phone technology, further development and exploration of mobile applications for detecting neonatal jaundice across all ethnic backgrounds is warranted.

Regarding cyanosis

11. In light of inequalities highlighted by the COVID-19 pandemic in adult studies, further UK based research to examine the small but potentially clinically significant differences in arterial oxygen saturation compared to pulse oximetry saturation in neonates from diverse race and ethnicity backgrounds is warranted.

