

From The National Perinatal Information Center: Making the Case: Accuracy of Race and Ethnicity Data Reporting

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The National Perinatal Information Center (NPIC) is driven by data, collaboration and research to strengthen, connect and empower our shared purpose of improving patient care.

For over 30 years, NPIC has worked with hospitals, public and private entities, patient safety organizations, insurers and researchers to collect and interpret the data that drives better outcomes for mothers and newborns.



National Perinatal Information Center

On July 2017, National Public Radio and ProPublica launched the Lost Mothers series. This was a turning point in the national conversation for maternal mortality; however, it created frustration and concern for those national organizations and hospitals who had been sounding the alarm of maternal mortality for years prior to this catalyst.

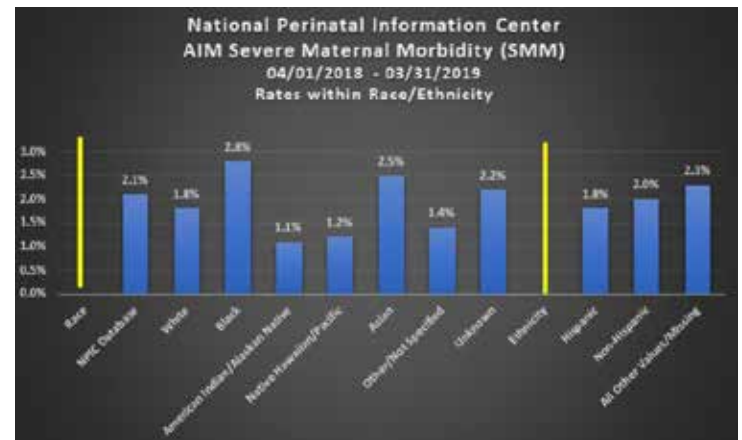
With the recent events surrounding racial inequality and injustice that have again surfaced throughout the United States, bringing data to this discussion continues to be a critical element to supporting hospitals, perinatal and neonatal units with their disparities reduction efforts. It is important to note that within this discussion, the race is not a risk factor, and should never be considered as such.

The National Perinatal Information Center provided an overview of Racial and Ethnic Disparities data to its members in the fall of 2019. This information was offered to serve as an additional adjunct to disparity work already underway at many organizations across the United States. However, the large part of the following discussion revolves around two unique attributes of race and ethnicity reporting: outcome disparities for Black women, and completion of data elements in the electronic medical record, particularly racial and ethnicity data reporting. In 2009, the National Academies of Sciences, Engineering, and Medicine (formerly the Institute of Medicine) published Race, Ethnicity, and Language Data: Standardization for Health Care Quality Improvement. This document highlighted a number of recommendations for racial and ethnicity data reporting; how-

ever, these recommendations show a wide variation on acceptance and implementation. To further illustrate the use of "unknown" or "other," specifically highlighted are Severe Maternal Morbidity (SMM), Severe Maternal Morbidity (SMM) among Hemorrhage Cases, and Neonatal birth weights of < 2500 grams and < 1500 grams, respectively.

AIM Severe Maternal Morbidity (SMM):

The National Perinatal Information Center provides Alliance for the Innovation of Maternal Health (AIM, <https://safehealthcareforeverywoman.org/aim-data>) comparisons that can provide comparisons for the organization, as well as an overall benchmarked rate. During the period 04/01/2018 – 03/31/2019, the following trends were noted:

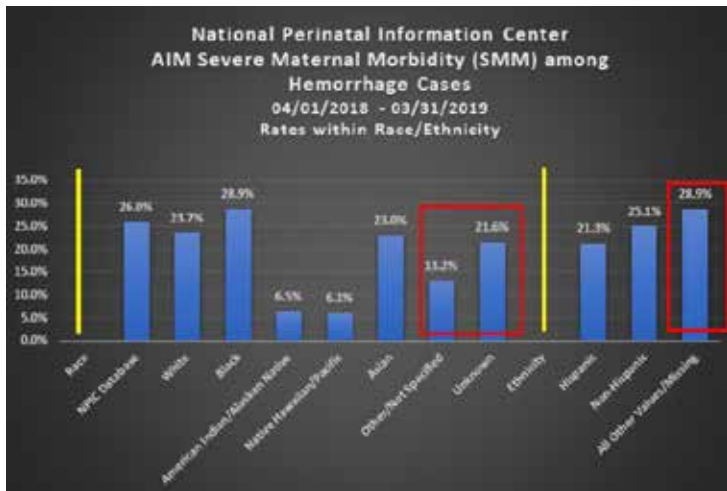


AIM Severe Maternal Morbidity among Hemorrhage Cases

Again, Black women reveal the highest rate within races of SMM among hemorrhage cases; however, there is an important facet of this data that cannot be overlooked. "Other" and "Unknown" are 13.2% and 21.6% within the cases, respectively. In addition, within ethnicity, 28.9% of hemorrhage cases are other or missing. The ability to track and identify racial and ethnic disparities within organizations and communities relies on accurate reporting of race and ethnicity at the time of admission as well as at discharge and processing of the medical record. This information highlights an important element of data collection that must be a priority for organizations that are intent on reviewing and acting upon disparities.

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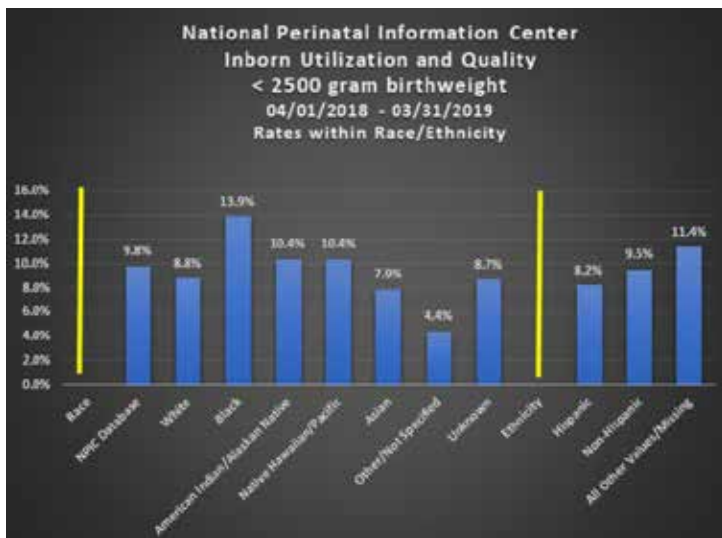
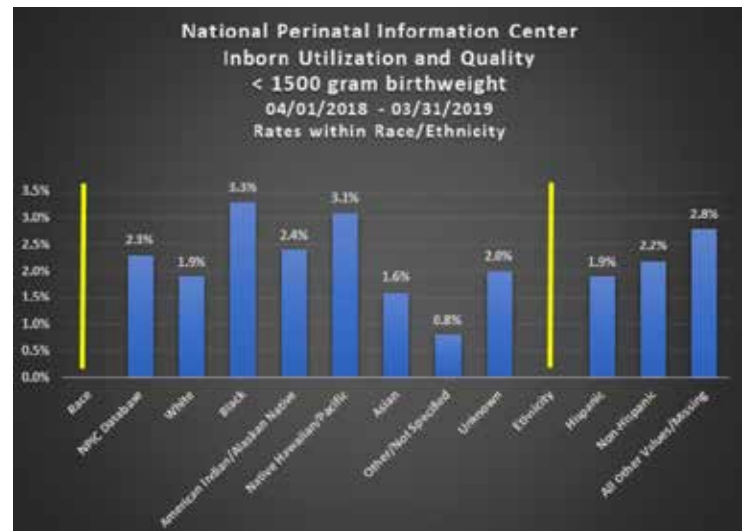


Very Low Birthweight (< 1500 grams)

Premature birth is a significant cause of infant and child morbidity and mortality (Glass et al., 2009). Babies weighing less than 1500 grams at birth can experience significant challenges to multisystem organ involvement, including high resource utilization and long NICU stays, which can compound challenges to parental involvement, particularly for those with socioeconomic challenges and other family responsibilities. Based upon several studies reviewing racial and ethnic disparity in the NICU environment, Black women are more likely to have more perceived stress, more depressive symptoms, and less social support than white women, regardless of income (Grobman et al., 2018). However, in this particular metric, "Other" and "unknown" data are much lower than the other metrics described, which again could reflect multidisciplinary care teams' documentation processes.

Low Birth Weight (< 2500 grams)

One of the most widely studied birth outcomes is birthweight, which is affected by conditions before and during pregnancy that can have an impact on intrauterine growth as well as gestational age (Ro, Goldberg & Kane, 2019). Infant birth weight is a common measure of infant and maternal health and well-being (Department of Health and Human Services, 2020). Infants weighing less than 2500 grams may experience significant cost and health problems that can exacerbate short and long-term costs of care. Within races, Black women have the highest rate of low birth weight babies within the NPIC Perinatal Center Database for this specific time period. Studies continue to support the finding that non-Hispanic Black women have the highest risk of low birthweight newborns, related to social determinants of health (SDOH) and "weathering," described in 1996 within a study of African American maternal age and birth weight as the "erosion of health of African American women as a result of social inequity" (Geronimus, 1996). It is important to note that race is not being described here as a risk factor. The rate of "Other" or "Unknown" within races, as well as "Missing" within ethnicity, is reduced for this data point, which may reflect both perinatal and neonatal documentation teams for racial and ethnicity reporting.



Discussion and Recommendations:

Based upon the NAESM/IOM Race, Ethnicity, and Language Data: Standardization for Health Care Quality Improvement subcommittee report, here are several of the standardized recommendations for enhancing and improving race and ethnicity reporting:

- 1) Self-Reporting: The opportunity for patients to directly self-report their race and ethnicity into an electronic health record with the expectation of privacy and confidentiality cannot be overstated. According to Polubriaginof and colleagues (2019), when patients directly recorded their race and ethnicity, 86% provided clinically meaningful information, and 66% of patients reported information that was discrepant with the electronic health record.
- 2) Training for frontline teams responsible for race and ethnicity reporting: According to the Subcommittee literature review, the comfort level of clinical teams and admissions/intake personnel was varied, and depending upon that comfort level, data may have been assumed and entered without expressly engaging with the patient. This discomfort was found to occur broadly and was not exclusive to one race of clinicians. Assuring adequate training of the importance of data reporting, as well as recognition of im-

plicit bias, provides a foundation for data reporting process improvement.

- 3) Interoperability of Electronic Health Records and data reporting: Organizations attempt to refine and build racial and ethnic reporting matrices that meet their own individual and system needs, but may create challenges when attempting to compare themselves to others throughout the US. OMB standards for data reporting may afford consistency in not only monitoring data within a hospital or system but also may be beneficial in benchmarking disparity improvement processes across organizations and nationally.

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The author has no conflicts of interests to disclose.

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