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The giving voice to mothers study: Communities of color speak of disrespect and inequity in childbirth

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Adverse perinatal outcomes among immigrants, refugees, and women of colors in the US are well- documented and disparities persist even when socio-economic background is considered. Through a participatory process, community members designed, content validated, and distributed a survey that capture patient-oriented data from persons of color, who gave birth inside and outside institutions. The survey included over 150 items on preferences and experiences of maternity care, including three validated instruments, the Mothers Autonomy in Decision Making (MADM) scale, Mothers on Respect index (MORi), and the Perceptions of Racism (PR) scale that measure experiences of respect, discrimination, and autonomy. Of the total sample (N2260), 37.3% were women of color (Black, Hispanic, Native, other), and 18% Medicaid recipients. Among participants of color, 20.5% were not satisfied with their role in decision making, and discrimination due to a difference in opinion with providers was more common (17%). Persons of color found it difficult to locate a care provider from their heritage, race, or culture, 66% vs 10% of White participants. Respondents of colors and low-income women (eg. Medicaid recipients) were more likely to report disrespectful treatment from care providers, and more likely to agree that they were pushed into accepting options their care provider suggested. Data suggest that both type of provider and place of birth significantly modulate outcomes and access, and institutional racism is a contributing factor. Our patient-led study confirms that marginalized women in the US experience less respectful maternity care, and reduced access to options for physiologic birth care.