Children's Hospital of Philadelphia PolicyLab

Pilot Grants

Examining Race and Ethnicity Data Evolution in Pediatric Care: National Trends and Influential Factors

Health Equity

Statement of Problem

Utilization of race and ethnicity data is near-universal in the conduct of medical research, disparities-specific research, internal quality initiatives, and, more recently, national quality measurement. As such, the implications for the reliability of race and ethnicity data are far-reaching, from delivery of patient care to potential public reporting and reimbursement practices. Researchers and others looking to use the data in their work have called into question its accuracy and gaps in collection that limit its usability and value

A growing body of evidence demonstrates that pediatric race and ethnicity data, as recorded in hospital administrative records, are often incomplete, subject to inaccuracies, and may change over time. However, the existing studies have leveraged hospital, city or state data. Given the extensive national variation in data collection practices, utilization of these regional data leave gaps in our knowledge around national trends, generalizability or variation by regions.

Description

Through this project, we are looking to identify and assess contextual factors that contribute to changes in documented race and ethnicity over the course of a pediatric patient's lifespan. We will do this by 1) determining the frequency of change in race and ethnicity in the Pediatric Health Information System (PHIS) database, and 2) identifying factors that are associated with change in race and ethnicity.

More specifically, we'll conduct a retrospective cohort study examining repeated report of race and ethnicity for individual patients in the PHIS database from 2010–2023 as well as examine the patterns of change within those for whom a multiracial identity is indicated at any time.

We'll use statistical models to see if changes in a person's race or ethnicity are linked to other factors we've already identified, like age, race, ethnicity, number of visits, where and when the visits happened, the size and location of the institution, and how the institution collects race and ethnicity data.

We hope identifying contextual factors that influence change in race and ethnicity documentation will inform national institutional efforts to develop reliable, accurate, and patient-centered approaches to race and ethnicity data collection.

Next Steps

Our team is collaborating with PHIS to complete the analysis in 2025. In the future, we plan to contextualize our findings by comparing them with existing literature on the reliability of race and ethnicity data. Additionally, we hope to develop policy recommendations to standardize data reporting practices and enhance the reliability of these critical variables in pediatric health research.

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