

Invited Commentary

Racial and Ethnic Disparities in Pediatric Ophthalmology Research

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Widespread racial and socioeconomic disparities exist in pediatric eye health access and outcomes.¹ According to a National Academies of Sciences, Engineering, and Medicine 2022 report, “Improving Representation in Clinical Trials and Research: Building Research Equity for Women and Underrepresented Groups,”² broad

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representation of race, ethnicity, and sex among research participants is essential to increase generalizability of study findings and improve health outcomes for all populations. Both the National Institutes of Health and the American Medical Association have encouraged diverse representation through race and ethnicity reporting mandates in clinical trial results and in medical and science journals, respectively. In this issue of *JAMA Ophthalmology*, Dihan and colleagues³ evaluated racial, ethnic, and sex representation in Pediatric Eye Disease Investigator Group (PEDIG) clinical trials.

The study authors compared participant enrollment by race, ethnicity, and sex across 41 PEDIG studies conducted from 1997 to 2022. They compared median enrollment to each group’s respective percentage representation in the 2010 US Census. The main study findings were that, among all PEDIG studies included, approximately 50% had underrepresentation of Asian, Black, and Hispanic participants. In contrast, females were represented proportionately across trials, and White participants were overrepresented. In a temporal analysis, there was a trend toward increased enrollment of Hispanic participants and decreased enrollment of White participants.

There are some limitations to this analysis, including not being able to directly compare participant data to the census demographic characteristics of the clinical study sites, the use of 2010 census data for a comparison group since PEDIG trials spanned 24 years, and a lack of data about reasons potential participants may have declined participation. Regardless, the study findings corroborate data reported in other pediatric clinical trials, including pediatric ophthalmology studies, about underrepresentation and overrepresentation of racial and ethnic groups. Similar results have been consistently noted in the adult ophthalmology population. Taken together, this evidence serves as a call to action within the ophthalmology and research communities at large to improve recruitment and enrollment practices and ensure that racial and ethnic minoritized groups are adequately and ethically represented in research.

To move forward, we must do a better job at understanding barriers to diverse representation in clinical trials, including patient and family literacy, health care professional communication, and unconscious biases in health care, and develop evidence-based initiatives to improve participation across all racial and ethnic populations. Barriers can be multifactorial and include mistrust in medicine or the research enterprise, espe-

cially in historically marginalized communities; speaking a primary household language other than English; geographic constraints; economic considerations, including out-of-pocket costs and time away from work; insurance coverage; lack of inclusion of diverse voices in study design and implementation; and underrepresentation of racial and ethnic minoritized groups among clinicians and researchers.^{4,5}

Many of these barriers merit further consideration in the context of the pediatric population. As of 2022, approximately 4 million children aged 18 years or younger were uninsured.⁶ Racial and ethnic minoritized populations and those most socioeconomically disadvantaged are disproportionately impacted by lack of insurance coverage. According to a recent analysis of the 2021 National Survey of Children’s Health, parents reported lower rates of visits to eye care professionals if they did not have insurance coverage or spoke a primary household language other than English.¹ This intersectionality of race and ethnicity with socioeconomic status means that individuals who need eye care the most also struggle the most to access any care, even in the routine and preventive setting.⁷ Furthermore, these children and their families likely have the least opportunities or means to support participation in clinical trials.

Geographic considerations are also a key factor in pediatric eye care, in both the clinical and research settings. Walsh et al⁸ reported substantial gaps in the availability of pediatric ophthalmologists across the United States, with a disproportionate number in the 4 most populous states and in areas with higher median household incomes. These geographic disparities can further compound limited participation in research; it is conceivable that the distribution of PEDIG clinical trial sites mirrors that of pediatric ophthalmology practices, making participation in studies less accessible to more remote rural and socioeconomically underserved communities. A national shortage of pediatric ophthalmologists further exacerbates this issue, especially given that there is inadequate representation of racial and ethnic minoritized groups across ophthalmology subspecialties. A recent report⁹ showed that only 10% of pediatric ophthalmology applicants came from racial and ethnic groups that are underrepresented in medicine.

These multiple challenges provide a panoply of opportunities to do better. Dihan et al³ highlight several important initiatives that can be implemented across the pediatric ophthalmology research community and have already been adopted by PEDIG. These include ensuring availability of translation services for all recruitment and study material; establishing internal research committees focused on equity, diversity, and inclusion of participants; mandating transparent reporting of race, ethnicity, and sex data in a standardized fashion; and targeting study enrollment numbers based on estimates of disease prevalence across different populations.

Beyond these measures, we should support advocacy efforts to improve insurance coverage and access to care for all children. Robust outreach efforts are needed to increase the diversity of the ophthalmology trainee pipeline, with a specific focus on building capacity in pediatric ophthalmology and serving geographically underserved areas. Initiatives such as the American Academy of Ophthalmology and Association of University Professors of Ophthalmology Minority Ophthalmology Mentoring program and partnerships with community health centers and federally qualified health centers are important steps in this direction. We should also expand efforts for community-based participatory research in pediatric ophthalmology, including representation of children and their parents or guardians. Inclusion of diverse voices helps

to establish community investment and ensure that research priorities are reflective of community needs.¹⁰ Such input can also help to build long-standing partnerships in the community that can further engender trust and benefit future research collaborations.

The work by Dihan et al³ highlights opportunities to improve collective efforts broadening representation of study participants across racial and ethnic groups. Large research consortia, such as PEDIG, can establish best practices to increase awareness and develop tools that will help with recruitment. The ultimate shared vision among all researchers is to ensure we have a diverse population of children in clinical research and generate evidence-based outcomes that will improve vision and eye health for the pediatric population at large.

ARTICLE INFORMATION

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