

VIEWPOINT

Strategies to Address Racial and Ethnic Disparities in Vision Care Research

Alice J. Liu, BA
Wilmer Eye Institute,
Johns Hopkins School
of Medicine, Baltimore,
Maryland.

**David S. Friedman,
MD, PhD, MPH**
Massachusetts Eye
and Ear, Harvard
Medical School,
Boston.

**Megan E. Collins,
MD, MPH**
Wilmer Eye Institute,
Johns Hopkins School
of Medicine, Baltimore,
Maryland; and Berman
Institute of Bioethics,
Johns Hopkins
University, Baltimore,
Maryland.

The pathophysiology of eye diseases is not always the same for patients of different racial and ethnic backgrounds. Two of the leading causes of blindness in older populations in the United States, age-related macular degeneration and glaucoma, have substantially different effects depending on racial origin.¹ Age-related macular degeneration is the leading cause of blindness among older White individuals and only infrequently affects Black individuals, whereas glaucoma is more prevalent among Black individuals.¹ In addition to racial differences, we know there are important distinctions between ethnicities in the prevalence of vision-threatening ocular conditions.² Furthermore, specific treatments or medications will affect marginalized racial and ethnic groups differently. These racial and ethnic differences are especially significant considering the disproportionate burden of treatable eye diseases in underserved populations,² often attributable to disparities in access and utilization of health care. More focus is needed on understanding the causes of racial and ethnic differences in both the prevalence of eye diseases and treatment response.

Two decades ago, the National Institutes of Health sent a clear message about the importance of prioritizing inclusion of women and marginalized racial and ethnic groups in clinical trials. More recently, the 21st Century Cures Act requires submission of valid analyses by sex/gender, race, and ethnicity for phase 3 clinical trials. Results from basic and clinical research strongly influence the future direction of policy and funding and, ultimately, the drugs and treatments that make it into clinical practice. To address issues of inequity in underserved populations, we must endeavor to ensure equitable inclusion of racial and ethnic groups in vision research. Underenrollment of marginalized racial and ethnic groups in clinical trials has been documented in ophthalmology, with most studies composed of majority White research participants.³ While there have been improvements in minority study participation, including Asian and Hispanic/Latino individuals since 2011, progress toward the goal of a diverse clinical study population in vision research is still needed.³

Barriers to Racial and Ethnic Minority Representation in Clinical Research

Several barriers contribute to the inadequate recruitment of racial and ethnic minorities into clinical studies. Marginalized groups have higher rates of being uninsured and less access to medical care, which limits investigators' abilities to recruit these populations.⁴ Even when these groups access care, the requirements of participation in trials may be too great given the time and transportation costs required for extended or addi-

tional clinical visits.⁵ Furthermore, study inclusion criteria based on English proficiency often limit non-native English speakers from participation.⁵

Trust in physicians and the research enterprise has been voiced by various racial and ethnic groups, including African American, Asian American, Latino, and Pacific Islander individuals.⁵ Prior work suggests that African American individuals are more likely to express fear about a physician's lack of transparency in discussing study risks.⁶ Contrary to these findings, others have not seen such differences in perception or willingness to participate in research studies.⁷ In terms of participant recruitment, physicians may have implicit biases that potentially hinder the enrollment of diverse participants.⁶ Health care practitioners may be more hesitant to approach racial and ethnic minority participants because of inaccurate perceptions that minorities are less likely to consent to research and more likely to demonstrate poor compliance with treatment routines.⁶

Recommendations to Promote Inclusion of Marginalized Groups in Clinical Research

Addressing the challenges of equitable minority representation in clinical research requires modifications at all levels including participation from clinical investigators, ethicists, institutional review board representatives, and members of scientific regulatory bodies.

To begin, investigators must be better educated about the importance of racial and ethnic minority inclusion in clinical trials. Opportunities to educate researchers about the value of diverse patient recruitment can be built into existing human subject protection training requirements. Investigators who are more knowledgeable about the importance of minority representation and learn effective strategies for recruitment and inclusion are more successful at enrolling minority populations.⁸

Another important strategy is to engage marginalized racial and ethnic community members as collaborators. Community-based participatory research involves building a project using a bottom-up approach and ongoing dialogue with the community to design a research agenda reflective of their needs. Another option is the engagement of current or former research participants. The Canadian Retinoblastoma Research Advisory Board is composed of patients with retinoblastoma, health care practitioners, researchers, and patient-engagement experts who, together, facilitate the development of meaningful retinoblastoma research.⁹ Current and past patients work with the team to identify mutually beneficial patient-research roles.⁹ Benefits to patient engagement include ensuring research funding is aligned with patient priorities, improving pa-

**Corresponding
Author:** Megan E.
Collins, MD, MPH,
Wilmer Eye Institute,
Johns Hopkins School
of Medicine, 600 N
Wolfe St, Baltimore,
MD 21287 (mcoll36@
jhmi.edu).

jamaophthalmology.com

JAMA Ophthalmology Published online October 8, 2020

E1

tient recruitment and retention, and dissemination of research that is layperson friendly.⁹

Another consideration is to increase collaboration with racial and ethnic minority clinicians and clinics that primarily service minority groups. This type of partnership can increase access to target participant populations, inform study design, and guide the creation of culturally relevant educational materials. This may also be an opportunity to invite multidisciplinary collaborators, such as anthropologists, to help the research team better navigate cultural dynamics. Incorporation of racial diversity onto the research team has also been associated with higher reported success in enrolling racial and ethnic minority populations.⁸

Lastly, a reexamination of study design and the role of federal agencies and institutional review board committees must be undertaken. Investigators should prepare recruitment materials that are layperson-friendly for minority participants, including handouts that are culturally sensitive, translated into multiple languages, and easy to comprehend. Offering access to support groups or educational materials also builds trust and facilitates ease of research participant recruitment and retention. Increased flexibility for trial locations or scheduling research visits outside of normal clinic hours are other options,¹⁰ although there may be feasibility issues with both.

Study criteria that exclude patients whose primary language is not English should be carefully assessed, particularly because language services and technology can overcome traditional barriers of enrolling patients not fluent in English. Because targeted outreach to marginalized populations will require more effort and money, federal agencies should recognize the need for additional funding to allow for appropriate compensation, transportation, and outreach needed to access these groups.¹⁰ Institutional review boards should take greater responsibility for providing rigorous guidelines on the need to include diverse study populations, which will send a clear message to the greater scientific community about this priority.¹⁰ However, increased efforts to recruit marginalized racial and ethnic groups should not undermine any of the existing regulatory requirements to protect the rights and welfare of vulnerable populations.

To tackle the elevated burden of eye diseases facing marginalized communities, we need to promise and fulfill our commitment to increased racial and ethnic inclusion in clinical trials. Without addressing this important issue, we risk perpetuating, rather than resolving current health disparities. Progress from investigators and institutions alike will help to alleviate the burden many underserved populations face in ophthalmology and vision care.

ARTICLE INFORMATION

Published Online: October 8, 2020.

doi:10.1001/jamaophthalmol.2020.3969

Conflict of Interest Disclosures: Dr Friedman reports personal fees from Bausch & Lomb, W. L. Gore, Novartis, Life Biosciences, Ix, Thea, and University of Vermont and grants from Icare Finland outside the submitted work. No other disclosures were reported.

REFERENCES

- Zhang X, Cotch MF, Ryskulova A, et al. Vision health disparities in the United States by race/ethnicity, education, and economic status: findings from two nationally representative surveys. *Am J Ophthalmol*. 2012;154(6)(suppl):S53-62.e1. doi:10.1016/j.ajo.2011.08.045
- Stein JD, Kim DS, Niziol LM, et al. Differences in rates of glaucoma among Asian Americans and other racial groups, and among various Asian ethnic groups. *Ophthalmology*. 2011;118(6):1031-1037. doi:10.1016/j.ophtha.2010.10.024
- Hamid M, Orlov S, De Lott L, Ling JJ, Woodward MA. Reporting and enrollment of women and racial minorities in ophthalmic clinical trials. *Invest Ophthalmol Vis Sci*. 2019; 60(9):5469.
- Abdus S, Mistry KB, Selden TM. Racial and ethnic disparities in services and the Patient Protection and Affordable Care Act. *Am J Public Health*. 2015; 105(suppl 5):S668-S675. doi:10.2105/AJPH.2015.302892
- George S, Duran N, Norris K. A systematic review of barriers and facilitators to minority research participation among African Americans, Latinos, Asian Americans, and Pacific Islanders. *Am J Public Health*. 2014;104(2):e16-e31. doi:10.2105/AJPH.2013.301706
- van Ryn M, Burke J. The effect of patient race and socio-economic status on physicians' perceptions of patients. *Soc Sci Med*. 2000;50(6): 813-828. doi:10.1016/S0277-9536(99)00338-X
- Wendler D, Kington R, Madans J, et al. Are racial and ethnic minorities less willing to participate in health research? *PLoS Med*. 2006;3(2):e19. doi:10.1371/journal.pmed.0030019
- Williams IC, Corbie-Smith G. Investigator beliefs and reported success in recruiting minority participants. *Contemp Clin Trials*. 2006;27(6): 580-586. doi:10.1016/j.cct.2006.05.006
- White E, Baddelyanage R, Shaikh F, Dimaras H. Meaningful patient engagement in research: lessons from retinoblastoma. *Pediatrics*. 2019;143(6):e20182166. doi:10.1542/peds.2018-2166
- Coakley M, Fadiran EO, Parrish LJ, Griffith RA, Weiss E, Carter C. Dialogues on diversifying clinical trials: successful strategies for engaging women and minorities in clinical trials. *J Womens Health (Larchmt)*. 2012;21(7):713-716. doi:10.1089/jwh.2012.3733