

Report on Research Compliance Volume 16, Number 5. May 01, 2019 Focused IRB Review Can Thwart Dangers of 'Race-Based' Research

By Theresa Defino

Would it be ethical, and appropriate, to conduct research that is focused on only one race of subjects? What questions should institutional review boards (IRBs) pose to investigators who present such protocols for approval, and how would race even be defined in a study of these types?

These and other thorny issues were the focus of a recent webinar, "Race-Based Medicine and Race-Based Research: Ethical Considerations for IRBs," hosted by Public Responsibility in Research & Medicine, also known as PRIM&R.

Three speakers from Temple University shared their insights during the 75-minute program: Kathleen Reeves, M.D., senior associate dean of health equity, diversity, and inclusion; Nicolle Strand, assistant director for research at the Center for Bioethics, Urban Health and Policy and an assistant professor at the Lewis Katz School of Medicine at Temple University; and Michael Henderson, associate vice president for research regulatory compliance and strategic initiatives in the Office of the Vice President for Research.

As the program description states, genomics and personalized medicine are advancing, along with an "increased awareness that 'race' is an inappropriate proxy for groups that may share a genetic background. However, proposals are still being submitted and approved at institutions across the country that assume that self-reported race correlates with biological/genetic difference."

Such studies "are scientifically out-of-date, as genetic evidence reveals that the difference between races is smaller than differences among individuals of any particular race. Furthermore, such studies, even when conducted with the best intentions, risk perpetuating racist stereotypes, inappropriately influencing clinical medicine, and reinforcing inaccurate ideas about biology and race." Race is now viewed as a "social construct, not a biological fact, and as individuals from different races partner and have children, self-reported race becomes less tied to ancestry."

Reeves spoke first, reviewing how, "historically, medicine and medical research have used race as a proxy or a shortcut for genetics." She noted that individuals "make a collective assumption that if people look like they share the same race, then they are more genetically similar than people who identify with a different race." But, added Reeves, "What we're learning now is that this assumption is wrong. It can also be damaging and contribute to the current ongoing [problems] associated with healthcare disparity."

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