

Changing the common rule to increase minority voices in research

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An article to be published in the *American Journal of Public Health* recommends changing the federal regulations that govern oversight of human subjects research ("the Common Rule") to address continued underrepresentation of minorities in research studies.

Co-written by Bill Rencher (M.P.H. '12), health access program director of the consumer advocacy nonprofit Georgia Watch, and Leslie Wolf, Georgia State University professor of law, the article, "Redressing Past Wrongs: Changing the Common Rule to Increase Minority Voices in Research," is part of a special issue on the Ethics of Human Subjects Research in Minority Populations.

The article responds to the underrepresentation of African-Americans and other [minorities](#) in research, an important [public health](#) problem because numerous diseases and health conditions, regardless of income, age, or gender, disproportionately affect these populations. Without adequate representation of minority populations in research, these health disparities will likely persist.

There are many reasons for the underrepresentation of minorities in research. Many point to the Tuskegee study in which the U.S. government followed hundreds of poor, rural African-American men with untreated syphilis for 40 years as a cause of mistrust in research.

However, "the history of medical and research abuses dates to slavery," Rencher says. "African-Americans may be disinclined to participate

because of long-standing suspicion with the medical establishment." They also may lack access to care, which means they are not asked to participate in the first place, and see few minority physicians or researchers.

"We recommend treating minorities as a vulnerable population for regulatory purposes, as is done for children, prisoners and pregnant women," Wolf says, "to focus the attention of those overseeing the studies. We continue to have problematic studies involving [minority populations](#). Our hope is creating special regulatory provisions will focus attention in ways that eliminate these problematic studies."

The article also suggests greater community consultation and increasing minority representation on Institutional Review Boards, organizations charged with reviewing research studies, to better provide greater minority input into the research oversight system.

Rencher and Wolf hope more attention to the concerns of communities affected will facilitate research that can find solutions to the health inequities that persist in the United States.

"The changes we're recommending alone are not going to solve the problem. There need to be other structural changes, such as more minority researchers and physicians. But we hope our article gets the conversation started," Rencher says.

The collaboration with Wolf on the article resulted from taking her human subject research course, which Rencher, an attorney, took as an elective for his master of public health degree through Georgia State's new School of Public Health.

Provided by Georgia State University

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