

# ARCHIVE NEWS RELEASE

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## New Findings on the Willingness of Minorities to Participate in Health Research

Bethesda, Maryland — New findings by researchers at the National Institutes of Health show that minorities participate in health research studies at the same rate as non-Hispanic whites when they are made aware of the study and meet the medical requirements. The findings counter the widely held notion that minorities are less willing to participate and lead the researchers to suggest that minority involvement is more a matter of access than attitude.

The study was led by researchers in the Department of Clinical Bioethics at the National Institutes of Health Clinical Center, the hospital at NIH. The work is published online December 6, 2005 in the medical journal *PLoS Medicine*, published by the Public Library of Science.

“In order to improve the health of our population, we must make health research accessible to all groups,” says Raynard Kington, NIH Deputy Director. “This NIH-supported study is a good example of research on how we do our research that can help us in making sure we have the best scientific knowledge base possible for eliminating health disparities.” Kington was one of the authors of the report. His research has focused on the relationship between social factors such as race and economic status and health.

“I think it’s going to surprise many people,” says Ezekiel Emanuel, M.D., Ph.D., chair of the Department of Clinical Bioethics and an author of the report. According to the study, it is widely claimed that racial and ethnic minorities are less willing to participate in health research, and many people attribute it to a distrust traced to past research abuses., the most notable being the 1932-1972 Tuskegee syphilis study. In that study, which was funded by the Public Health Service, hundreds of poor African American men in Alabama were followed for decades without being told they had syphilis and were prevented from getting penicillin to treat their syphilis.

But the data from this new study finds that when minorities are given the opportunity to participate in health research, they do so at the same rate as non-Hispanic whites.

“The big take home message here is that the main barrier probably is not the attitudes of African Americans and other minorities,” Emanuel says. “The main barrier is access, knowledge that these studies exist, eligibility criteria that ensure minorities can participate, and overcoming logistical barriers that exist,” such as the location of the study or the need for child care.

The research team did a comprehensive search of the medical literature to identify published trials that reported consent rates by race and/or ethnicity. The team identified and reviewed 20 studies that involved more than 70,000 patients. Most of studies were conducted in the United States and most of participants from minority groups were African Americans or Hispanics. Given that research was based on the enrollment decisions of more than 70,000 people over two decades in a variety of different types of research studies, from epidemiology to drug to surgical studies, the authors say they believe their findings are robust.

The researchers found only small differences in the willingness of minorities to participate compared to non-Hispanic whites. But the researchers found big differences when it came to who was asked to participate. In seven of the 17 clinical and surgical intervention studies, enrollment was discussed with relatively few people from minority groups.

The authors say efforts to increase minority enrollment in trials should focus on improving access rather than changing minority attitudes. The researchers offer a number of suggestions. They include: informing minority groups about specific trials; choosing study sites that minorities can easily access; partnering with community health clinics and other sites where a substantial number of minorities receive medical care; addressing logistics that could undermine minority participation such as the need for child care and reimbursement for travel expenses.

“Study participants should reflect our society as a whole to ensure that findings benefit the most people,” says John I. Gallin, M.D., director of the NIH Clinical Center. “Identifying more ways to reach out to people who are willing to take part in research can advance medical science and improve the health of our nation.”

This research was done in collaboration with researchers from the Office of Behavioral and Social Sciences Research at the National Institutes of Health, the Centers for Disease Control and Prevention and Yale University School of Medicine. Authors: David Wendler, Raynard Kington, Jennifer Madans, Gretchen Van Wye, Heidi Christ-Schmidt, Laura A. Pratt, Otis W. Brawley, Cary P. Gross, Ezekiel Emanuel.

The NIH Clinical Center is the clinical research hospital of the National Institutes of Health. Through clinical research, physicians and scientists translate laboratory discoveries into better treatments, therapies and interventions to improve the nation’s health.

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