

# Researchers tackle racial/ethnic disparities in HIV medical studies

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A New York University College of Nursing (NYUCN) research team found that a social/behavioral intervention vastly increased the number of African American and Latino individuals living with HIV/AIDS who enrolled in HIV/AIDS medical studies. The intervention, designed by researchers at the NYUCN's Center for Drug Use and HIV Research (CDUHR), found that nine out of ten participants who were found eligible for studies decided to enroll, compared to zero participants among a control group.

The study, called "ACT2," addresses a long-recognized problem: the racial/ethnic groups most affected by HIV are chronically under-represented in HIV/AIDS medical research. While 50% of all people living with HIV/AIDS are African American/Black, they comprise a mere 30% of those enrolled in HIV/AIDS [medical studies](#). Likewise, Latinos are also under-represented in such studies in many settings. This lack of proportional representation raises a number of questions, including about the applicability of medical research findings to the groups most affected by HIV/AIDS.

"The issue of under-representation of these racial/ethnic groups is well known, but it's a complex problem and not that easy to change," said Marya Gwadz, PhD, a senior research scientist at NYUCN and lead author of the study. "Our study is the first to have tested social/behavioral intervention strategies to reduce barriers to HIV medical studies for these under-represented populations."

The ACT2 study demonstrated a thirty-fold increase in rates of screening for HIV/AIDS medical studies among African Americans and Latinos living with HIV/AIDS compared to a control group. As reported in the June 2014 issue of *AIDS and Behavior*, half of those screened were found eligible for a study, and among those found eligible, 90% enrolled in at least one HIV/AIDS medical study. Among participants in the control group, screening was rare and, as a result, none in the control group enrolled.

"There are misconceptions that African Americans and Latinos are not interested in HIV/AIDS medical studies," said Dr. Gwadz. "We found that members of these groups are typically fearful of medical studies and also have socioeconomic barriers to accessing them. Yet we found that in the context of the ACT2 intervention program, which allows participants to learn more about trials, articulate these fears, and gain access to trials, they are very willing to explore the possibility of

participating, and if they are found eligible and the study is right for them, also eager to enroll."

The ACT2 intervention uses a potent peer-driven recruitment and peer education intervention approach, combined with brief, structured small group and individual sessions delivered by trained counselors. The sessions focused on increasing awareness about the problem of disproportionate representation of people of color in HIV/AIDS medical studies, while also allowing participants to voice fears about these studies. Fear of medical studies is common among African American and Latino populations, and is rooted in the long-standing mistreatment of people of color in U.S. medical research. Participants in the control arm received a time-matched, small-group health education program.

The researchers focused on enrollment into both therapeutic/treatment clinical trials and biomedical observational studies, which have similar rates of racial/ethnic under-representation. They found that participants were much less likely to be found eligible for trials testing new treatments or therapies for HIV/AIDS, compared to observational studies that do not involve testing new treatments.

"While social/behavioral interventions such as ACT2 are important for increasing motivation and knowledge of medical studies, and providing support to navigate the complexity of screening and enrollment into studies among this population, we believe achieving appropriate racial/ethnic representation will require modification of study inclusion criteria to increase the proportion found eligible for therapeutic studies," noted Noelle Leonard, PhD, a co-investigator of the study at CDUHR.

Both the intervention and control groups were notified about the thirty ongoing HIV/AIDS medical studies in the New York City area where the study was conducted and were presented with the option to initiate screening to determine their eligibility. As part of the intervention,

participants in the ACT2 intervention group were offered help in navigating the structural and personal barriers they might encounter to completing the often-complex screening process, while those in the [control group](#) were not offered navigation.

ACT2 draws its success by incorporating both the Theory of Normative Regulation—which posits that behaviors of individuals are amplified through their social groups—and Motivational Interviewing, a health behavior change method for fostering individuals' intrinsic motivation to make positive changes without applying pressure or judgment.

"Our participants have told us they want to contribute to their communities through research and help those with HIV who come after them," said Dr. Gwadz. "Yet the impediments they typically experience to participating in medical studies deny them this opportunity. ACT2 helps build a bridge between HIV/AIDS medical studies and communities of color."

Of the thirty medical studies available during the study period, twenty-three (76.6%) were therapeutic studies and seven (23.4%) were observational studies. Yet despite the vast majority of the studies being therapeutic, only 4% of ACT2 participants screened were eligible for such studies. Instead, the majority of [participants](#) (84.4%) were found eligible for observational studies.

"It is imperative that scientists who develop HIV/AIDS medical studies consider the implications of highly restrictive inclusion criteria and other design features on the participation of under-represented groups, while at the same time maintaining study validity," said Dr. Leonard.

The ACT2 intervention is designed to be administered by Master's level clinicians, and is comprised of six hours of staff-guided intervention sessions, and individualized navigation during the screening process, as

needed. Participants also have the opportunity to independently educate their peers about medical studies, which is in itself a form of intervention. "ACT2 does not require a great deal of staff time to implement," said Dr. Gwadz, "but can potentially make a big difference in rates of enrollment among racial/ethnic minorities." ACT2 is one of the programs in the Substance Use and Mental Health Services Administration's (SAMHSA) [National Registry of Evidence-based Programs and Practices](#).

Provided by New York University

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