



# HIV/AIDS Clinical Trials & People of Color

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## What We Know

Racial and ethnic minority groups in the United States continue to experience disparities in health care, with many lower health outcomes than the white population. HIV/AIDS is no exception to this trend. Racial and ethnic minority groups in the U.S. make up 24% of the U.S. population yet they represent 67% of new AIDS cases. <sup>1</sup>

Racial and ethnic minorities are also less likely to participate in HIV/AIDS Clinical Trials. A review of trial participation over several years showed that while African Americans make up 33% of those receiving treatment for HIV/AIDS in the United States, they comprise 23% of trial participants. The same study showed that while Hispanic individuals make up 15% of those receiving care, they make up only 11% of trial participants. <sup>2</sup>

This study did not provide similar information about Asian & Pacific Islander Americans and Native Americans in HIV/AIDS Clinical Studies. There is concern, however, that these communities are also under-represented.

	Receiving Care	In Trials
African American	33%	23%
Hispanic	15%	11%
White	49%	62%

## Common Barriers to Trial Participation

There are many different barriers that may make it more difficult for people of color to participate in trials. These include mistrust, economic issues, and communications issues: <sup>3</sup>

- **Mistrust:** Particularly in the case of African Americans, trial participation must be viewed in a historical context. A review of past medical trials on African Americans reveals a number of brutal and unethical trials culminating in the infamous Tuskegee Study. <sup>4</sup> One way trial sites address the issue of mistrust is by actively engaging community representatives to serve on local community advisory boards.
- **Economic Issues:** Trial participation requires time and commitment for trial participants which is not always easy for those who have to miss work or arrange daycare for their children to participate in a trial. Local sites address this issue by providing vouchers or travel reimbursement to trial participation.
- **Communication Issues:** Many communities of color do not have all the information they need to make sound decisions about trial participation. Local sites can address this by community outreach and patient education, making sure that the information is culturally appropriate and translated into different languages as appropriate.

- **Other Issues:** This is not meant to be a complete list. There are many other factors that may impact ability to participate in a trial including language, family issues, immigration status, time off work, etc... As a concerned community member, you can help identify issues and suggest ways to address them.

## The Role of Federally Funded Research Networks

The Community Programs for Clinical Research on AIDS (CPCRA) research network was established in 1989 specifically to expand research opportunities to communities of color, women, and others infected with HIV such as injection drug users. Approximately 60% of CPCRA trial participants are people of color. The CPCRA is one of several research networks supported by the National Institutes of Health Division of AIDS (DAIDS).

Each DAIDS Research Network strives to have trial participants representative of the communities impacted by HIV/AIDS. Research networks and local research sites put together recruitment and retention plans that should include information on how they plan to outreach to the communities most impacted by the epidemic. These networks can, however, fall short of this goal.

## The Role of the Community

Community members can play an important role looking at how clinical trials are structured to encourage diverse representation in studies. This can include reviewing and providing input on how the study is designed, where the trial will take place, and the overall goals and plans for recruiting trial participants.

Community members can also work with their local research site to encourage diverse representation in trials. This can include giving input on the local site recruitment plan, hours that the local site is open, site reimbursement policies, and any other factors local community members identify.

Studies funded by the National Institutes of Health (DAIDS Division of AIDS), have vehicles in place to gather community input at both the local and global level. Privately funded clinical trials may or may not have formal structures in place; however, community members and advocacy groups can play an important role in influencing these studies as well.

### For more information on AIDS Research and Communities of Color

#### **National Minority AIDS Council**

1931 13<sup>th</sup> Street, NW, Washington, DC 20009, (202) 483-6622  
[www.nmac.org](http://www.nmac.org)

The National Minority AIDS Council (NMAC), is a national organization dedicated to developing leadership within communities of color to address the challenges of HIV/AIDS.

<sup>1</sup> Centers for Disease Control and Prevention HIV/AIDS Surveillance Report, Year-end edition, Vol. 10, No 2, December 1998

<sup>2</sup> New England Journal of Medicine 2002; 346; 18: 1373-1382

<sup>3</sup> Journal of the National Medical Association 1996; 88: 630-634

<sup>4</sup> Journal of the National Medical Association 1996; 88: 630-634