

African Americans and Clinical Research



Education before Participation

CISCRP is an independent non-profit organization focused on educating and informing the public about clinical research participation. CISCRP is not involved in recruiting patients for clinical trials nor is it involved in conducting clinical trials.

If you've ever taken a pill or been treated for a sickness, then you've seen the benefit of clinical research. Each year, thousands of African Americans take part in clinical research projects that help find ways to prevent, treat and cure sickness. Clinical research helps African Americans and all people enjoy better health.

What is a Clinical Research Project?

Clinical research projects, also known as clinical research studies and clinical trials, are research studies that measure the safety and effects of new treatments and procedures in human volunteers.





Why African American Volunteers are Needed

MANY ILLNESSES

like asthma, diabetes, heart disease, HIV/AIDS, and certain kinds of cancer affect African Americans more than other people. Yet, little is known about how African Americans respond to treatment. African American volunteers help scientists learn how different treatments affect African American people. When African Americans take part in clinical research, they help improve the health of all people.

Clinical Research Then and Now

FOR MANY YEARS, most clinical research projects were done on white men only. African Americans, women and other minorities were not included in them. When African American people were involved, the studies were sometimes dangerous and even harmful. That is no longer the case. Clinical research projects today welcome the participation of minorities and women, and they are monitored for their safe and ethical treatment of volunteers.



How African American Participants are Protected

SOME AFRICAN AMERICANS still remember past abuses like the Tuskegee Experiment in which syphilis treatment was withheld from a group of African American men for many years. They wonder if something like that could happen today.

The answer is, no. Federal guidelines and codes of ethics are designed to protect clinical research volunteers from harm. In addition, a panel of professionals and community members is responsible for monitoring study safety and safeguarding volunteer rights in every clinical research project.

Things to Consider Before Volunteering

BEFORE TAKING PART in a clinical research project, you'll want to look at the possible benefits and risks.

Benefits

- ◆ Getting treatment for an illness when no other treatment exists
- ◆ Receiving expert care for your condition
- ◆ Having early access to new treatments
- ◆ Knowing your participation is helping others

Risks

- ◆ Not being able to choose your treatment
- ◆ Receiving a treatment that may not work as planned
- ◆ Experiencing unpleasant or serious side effects



What You Need to Know

BEFORE YOU ENROLL in a clinical research project, it is a good idea to learn as much as you can about the project and your role in it. Ask questions, search the library or Internet for information (*See 'Learn More About Clinical Research' on back*), and seek the advice of family members or a trusted doctor, clergyman or friend. Speak to the research team about what will be done and your rights as a participant. If you need help understanding what you have been told, ask the investigators and study team to explain it to you. Remember, *your participation in clinical research is strictly voluntary* and you can drop out at any time.



Questions to Ask Before Participating in a Clinical Research Project

WHEN DECIDING whether to participate in a clinical research project, you may want to ask some of the following questions.

- What is the purpose of this project?
- Who is going to be in it?
- Will I know which treatment I am getting?
- What has been learned about the study treatment so far?
- What will I be asked to do?
- How long is the project going to last?
- Will I have to pay for any part of the project?
- Will my insurance cover the costs?
- Will I be reimbursed for travel costs associated with the study?
- How will I know if the treatment is working?
- If the treatment works for me, can I keep using it after the project ends?
- What will happen to me if the treatment doesn't work?
- Will anyone else know about my participation?
- How will this project help my family or my community?

Learn More about Clinical Research

There are many ways to find out about clinical research. Your doctor and library are good places to start. Health organizations like the American Cancer Society, the American Lung Association, the American Diabetes Association, and the Parkinson's Disease Foundation offer information about clinical research projects on specific illnesses. You also can get general information by calling or visiting the following places:

www.ciscrp.org

1-877-MED HERO (1-877-633-4376)

A non profit organization dedicated to educating and informing the public about clinical research participation.

www.SearchClinicalTrials.org

1-877-MED HERO (1-877-633-4376)

Public service that compiles clinical trial listings from multiple sources. You can also request a free search for clinical trials in your area.

<http://clinicaltrials.gov>

This service of the National Institutes of Health contains current information about thousands of federal and private clinical research projects.

www.fda.gov/oashi/clinicaltrials/clintrialdoc.html

Find answers to basic questions about clinical research on this site run by the U.S. Food and Drug Administration.

www.cc.nih.gov/participate.shtml

Phone 1-800-411-1222, TTY 1-866-411-1010

Learn more about current clinical research projects and clinical research participation from the National Institutes of Health.

<http://nmanet.org/index.php?/NatProgList/ctpri>

The National Medical Association provides information about health, medicine and clinical research projects for African American people.

www.omhrc.gov

1-800-444-6472

Visit the site of the National Office of Minority Health for information about minority health issues in English and Spanish.

