African Americans and Clinical Research

If you have ever taken a pill or been treated for an illness, you have seen the benefit of clinical trials. Each year, thousands of African Americans take part in clinical trials to help find ways to prevent, treat, and cure illness. Clinical trials are an essential part of helping African Americans and all people enjoy better health.

What are Clinical Trials?

Clinical trials, also known as "clinical research studies", or "clinical studies", are studies in human volunteers that try to answer specific health questions. Some clinical trials measure the safety and effectiveness of potential new treatments. Other clinical trials observe health issues and behaviors in large groups of people.

Why We Need Your Help

Many illnesses such as sickle cell anemia, asthma, diabetes, heart disease, HIV/AIDS, and certain kinds of cancer, such as prostate cancer, affect African Americans more than other people. Yet, little is known about how they respond to treatment, so African American volunteers are needed to help scientists learn how different treatments affect them. When taking part in clinical trials, African Americans help improve the health of all people and provide greater understanding of the differences between illness rates and the impact of potential treatments for different parts of the population.

CISCRP is not involved in recruiting volunteers for clinical trials, nor is it involved in conducting clinical trials.

Clinical Trials Then and Now

For many years, most clinical trials were done on white men only. This meant that groups such as African Americans, other minorities, and women were not included. But today, all people have the opportunity to participate in clinical trials, and those clinical trials are closely monitored for their safe and ethical treatment of volunteers.

How You Are Protected If You Participate

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. People wonder if something like that could happen today.

The answer is no. Federal guidelines and codes of ethics are in place to protect clinical research volunteers from harm. In addition, an Institutional Review Board, a panel of professionals and community members, is responsible for approving the study plan, checking participant safety, and protecting volunteer rights in every clinical trial.

What You Need to Know

Before you enroll in a clinical trial, it is a good idea to learn as much as you can about it. You may be interested to know that there are different kinds of clinical trials. Some need healthy volunteers while other clinical trials seek volunteers with a particular disease or condition.

A clinical trial is conducted according to a plan called a protocol, which describes:

- What types of volunteers may enter the study
- The schedules of tests and procedures, study medications and dosages
- Length of the study
- Number of study visits

Based on the requirements of the protocol, you may or may not qualify for a specific clinical trial.

If you qualify for the clinical trial, you will be told the potential risks and benefits of the study and asked to agree in writing to follow the protocol. This is called giving informed consent.

Things to Consider Before Volunteering

BEFORE TAKING PART in a clinical trial, consider the possible benefits and risks.

BENEFITS

The investigational treatment studied in a clinical trial may or may not benefit you personally, but the benefits of participating are:

- Receiving expert study-related care for your condition
- Having early access to potential new treatments
- Knowing your participation may help others

RISKS

Clinical trials study investigational treatments, therefore, some information about the study treatments are unknown. Some risks include:

- Not being able to choose your study treatment
- Receiving a study treatment that may not be effective
- Experiencing unpleasant or serious side effects

Remember, your participation in clinical trials is strictly voluntary and you can drop out at any time for any reason. Your decision to withdraw will not impact care or other benefits to which you are entitled.

To help you decide if you should participate in a clinical trial, ask questions, search the library or Internet for information, and seek the advice of family members or a trusted doctor, clergyman or friend.

Learn More About Clinical Trials

GENERAL RESOURCES

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 trials

https://www.cc.nih.gov/participate1.html
Phone 1-800-411-1222, TTY 1-866-411-1010
Learn more about current clinical trials and participation from the National Institutes of Health.

https://www.nmanet.org/
The National Medical Association provides information about health and medicine for African American people.

http://minorityhealth.hhs.gov/
1-800-444-6472 | Visit the site of the Office of Minority Health forinformation about minority health issues in English and Spanish.

Visit **CISCRP.org** for more information, including disease and condition-specific resources

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CISCRP

CISCRP is an independent non-profit organization dedicated to engaging the public and patients as partners in the clinical research process through education and outreach programs. CISCRP is neither involved in recruiting patients for clinical trials, nor is it involved in conducting clinical trials.

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Questions to Ask Before Participating in a Clinical Trial

- What is the purpose of this clinical trial?
- Why would researchers think the study treatment might work for me?
- What are my treatment and clinical trial options?
- How will this clinical trial help my family or my community?
- What will I be asked to do?
- How long is the clinical trial going to last?
- What are the possible risks?
- Will I have to pay for any part of the clinical trial, and will I be reimbursed for costs of travel, parking, or meals incurred while I am in a clinical trial?
- If the study treatment works for me, can I keep using it after the clinical trial ends?
- How will this study affect my daily life?
- Will anyone else know about my participation?

"Education Before Participation"

"African Americans and Clinical Research" is part of CISCRP's Education Before Participation resource series.

REVIEWED BY A CISCRP EDITORIAL PANEL

An editorial panel of patients, public, and professional representatives reviewed this educational brochure.