

# Black 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 Black Americans take part in clinical trials to help find ways to prevent, treat, and cure illness. Clinical trials help all people enjoy better health.



Center for Information and Study  
on Clinical Research Participation

## Questions to Ask Before Participating in a Clinical Trial

What is the purpose of this clinical trial?

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Why would researchers think this treatment might work for me?

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What are my treatment options?

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How will this clinical trial help my family or my community?

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What will I be asked to do?

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How long is the clinical trial going to last?

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What are the possible risks?

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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?

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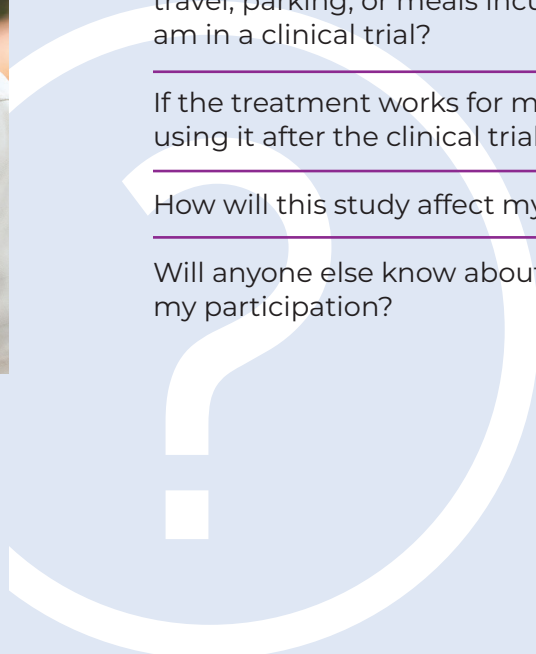
If the treatment works for me, can I keep using it after the clinical trial ends?

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How will this study affect my daily life?

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Will anyone else know about my participation?



## 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, disproportionately affect people who are Black. Volunteers are needed from the Black community to help scientists learn how the potential treatment will work in the people who may take it if approved. When the people who join in clinical trials reflect the people who are affected by the diseases being studied, the health of all people is improved.

## Clinical Trials Then and Now

FOR MANY YEARS, most clinical trials were done on white men only. But today, clinical trials welcome the participation of all people, and those clinical trials are closely monitored for their safe and ethical treatment of volunteers.

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

## 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 Black 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 monitoring study 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 needing treatment.

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 asked to agree in writing to follow the protocol. This is called giving informed consent.





## Things to Consider Before Volunteering

A clinical study is also known as a “clinical research study,” a “research study,” or a “clinical trial,” and aims to answer specific questions about your health and wellness. BEFORE TAKING PART in a clinical trial, certain information should be considered:

### WHAT ARE SOME POSSIBLE BENEFITS OF MY PARTICIPATION?

- Knowing your participation may help others by contributing to medical research and treatment advances
- Receiving study-related medical care for the condition being studied

### WHAT ARE SOME POSSIBLE RISKS OF MY PARTICIPATION?

- A study medication, therapy or device may not be effective
- Experiencing unpleasant or serious side effects as a result of the study medication, therapy or device
- Participation in the clinical study may be time consuming

To help you decide if you should participate in a clinical trial, ask questions, search the library or Internet for information (See Learn More About Clinical Trials on back), and seek the advices of family members or a trusted doctor, clergyman or friend.

**Remember, your participation in clinical trials is strictly voluntary and you can drop out at any time for any reason.**

## Learn More About Clinical Trials

### GENERAL RESOURCES

[www.SearchClinicalTrials.org](http://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 for information about minority health issues in English and Spanish.

Visit [CISCRP.org](http://CISCRP.org) for more information, including disease and condition specific resources



### “Education Before Participation”

“African Americans and Clinical Research” is part of CISCRP’s Education Before Participation resource series.



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



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 services also assist clinical research stakeholders in understanding public and patient attitudes and experiences in research to improve study volunteer participation. CISCRP is neither involved in recruiting patients for clinical trials, nor is it involved in conducting clinical trials.

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