Finding Treatments Together

Information about clinical research participation for Black and African American people

Why are clinical trials important?

Clinical trials are the best way to find out if new treatments or vaccines work and how safe they are.

If clinical trials show that a new treatment works and is safe, then it can be approved to be used by the people who need it.

Not all clinical trials test a new treatment or vaccine. "Observational" studies collect information about people's health during their normal care. This helps researchers learn more about specific health issues.

Why should clinical trials have diverse participants?

Treatments and vaccines might not work the same in people of different races, ethnicities, ages, or sexes.

To find treatments and vaccines that work and are safe for everyone, people from all backgrounds need to be represented in clinical trials.

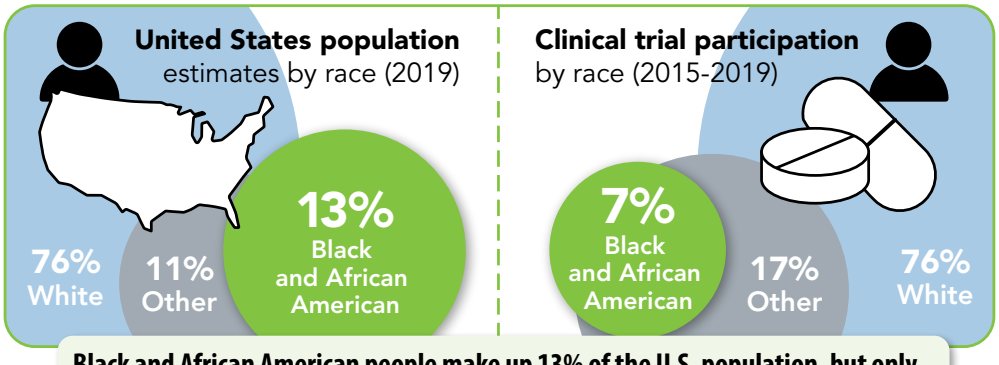
Why have Black and African American people not been represented in clinical trials?

Black and African American people are not always made aware of opportunities to participate in research. The research community is actively working towards including Black and African American participants in clinical trials to make sure that treatments work and are safe for people in these communities.

Tuskegee Study, 1932 to 1972

The Tuskegee study is an example of poor treatment of research participants. In this study, researchers withheld a treatment for syphilis from Black male participants. This unjust treatment led to changes in the way that clinical trials are run and how participants are protected.

Black and African American people have been underrepresented in clinical trials.



Black and African American people make up 13% of the U.S. population, but only 7% of the participants in trials for treatments approved from 2015 to 2019.

sources: FDA Drug Trials Snapshots Summary Report; United States Census Bureau

Many Black and African American people say they would take part in clinical trials if asked.

source: National Institutes of Health

The Tuskegee study is only one reason why some people may mistrust doctors or the research community. Unequal treatment of Black and African American people continues to exist in our modern health care system. By acknowledging these inequalities, researchers can take steps to correct them and to make sure that Black and African American people receive unbiased treatment.

How are you protected if you participate?

Federal laws and guidelines protect the safety of clinical trial participants. Clinical trials must:

- follow guidelines that make sure trials are ethical
- include a process called informed consent to fully inform people about the trial before they can agree to be in it
- be approved by an expert group called an institutional review board, also called an IRB, that makes sure the trial is fair and as safe as possible

What are the risks and benefits of participating in a clinical trial?

Possible risks

- The treatment in the trial may not help you.
- You may have side effects from the trial treatment.
- You may have frequent testing or blood draws.
- You may need to set aside time for participation.

Possible benefits

- You may have early access to advanced treatments for your condition.
- You may have access to treatment when no approved treatment exists.
- You will help researchers learn more about how a treatment affects your community.
- Your health may be watched by the trial doctors and nurses.

If you are thinking about participating in a clinical trial, be sure to talk with your doctor about the risks and benefits that may apply to you.

What are other ways you can get involved?

Joining a clinical trial that tests a new treatment for your illness or condition is only one way to participate in clinical research. Here are other ways to participate:

- Volunteer for an observational study that only collects health data.
- Join a trial as a "healthy volunteer" so researchers can collect data on how a new treatment acts in the body before giving it to patients.
- Sit on an institutional review board or a patient advisory board.
- Talk with your family and friends to raise awareness about clinical research in your community.

You may want to discuss your decision with a friend, family member, or someone in your faith community.

Remember that participating in a clinical trial is optional. You can withdraw your consent to participate at any time for any reason. The staff at the trial site will help you to do this safely.

How can you find more information?

If you have a specific condition, the patient advocacy organization for your condition may have a list of clinical trials. Your doctor may also know about clinical trials for your condition. If you would like to learn more about current clinical trials, call 1-877-MED-HERO.

For more information on the topics in this brochure, go to:

findingtreatmentstogether.org

This brochure was developed together with members of African American and Black communities and experts who work within those communities. It was also user-tested and reviewed with patients, the public, and health professionals. They all helped to make sure it is clear, non-biased, and culturally relevant.

CISCRP is an independent non-profit organization dedicated to engaging the public and patients as partners in the clinical research process.

CISCRP does not recruit patients for clinical trials and does not conduct clinical research. CISCRP is also known as the Center for Information and Study on Clinical Research Participation.

Visit www.CISCRP.org or call toll free 1-877-633-4376

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