

Finding Treatments Together

An introduction to clinical trials for Hispanics and Latinos



CISCRP

Center for Information & Study
on Clinical Research Participation

Why are clinical trials important?

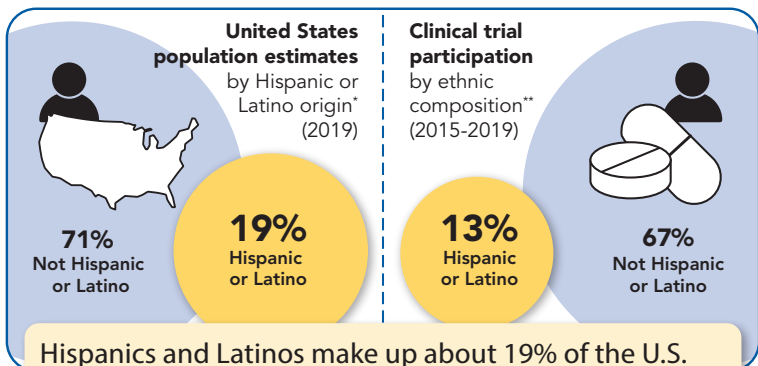
Clinical trials are the best way to study treatments or vaccines to learn if they work and how safe they are. If clinical trials show that a new treatment works and is safe, then it can be approved to be used by the people who need it.

Being in a clinical trial is your choice. To make the best decision for you, it is important to fully understand the risks, benefits, and how the trial might affect your daily life.

There are also other types of clinical research, such as trials with treatments that have already been approved.

Why should clinical trials have diverse participants?

Treatments or vaccines may affect people of different ages, sexes, races, or ethnicities in different ways. It's important for Hispanics and Latinos to be involved in clinical trials so we know how new treatments work and if they are safe for people from these communities.



Hispanics and Latinos make up about 19% of the U.S. population, but only 13% of the participants in trials for treatments approved from 2015 to 2019.

*10% missing or not reported; source: United States Census Bureau

**20% missing or not reported; source: FDA Drug Trials Snapshots Summary Report



Why have Hispanics and Latinos not been represented in clinical trials?

Lack of awareness

Many Hispanics and Latinos are not made aware of clinical trials and do not realize they can participate. It is important to talk to doctors and community health workers about clinical trials. But, they may not always know about clinical trials or keep a list of trials.

You can speak with organizations such as non-profits and recruitment companies that help people find trials. There is more information about this near the end of this brochure.

Language concerns

You have the right to communicate with the clinical trial staff in the language that is most comfortable for you.

You can ask for an interpreter, or for a doctor or community health worker who speaks Spanish. You can also request any documents in the language of your choice.

Mistrust of healthcare and clinical research

Hispanics and Latinos experience unequal treatment in healthcare. Mistrust of doctors and researchers might make some people unlikely to participate in clinical trials.

By acknowledging these inequalities, researchers can take steps to make sure that all people receive unbiased treatment.

Concerns about being required to stay in a trial

Being in a trial is optional. Agreeing to be in a trial does not take away any of your rights.

You can stop being in a trial at any time and for any reason. The trial staff will help you do this safely.

Concerns about being harmed

There is always some risk of being harmed in a trial, and the risks are different for every trial. But, decades of research have helped design trials that keep participants as safe as possible.

All the potential risks must be clearly explained to you before you agree to be in a trial. And, the trial staff and other researchers will monitor your safety throughout the trial.

How are you protected if you participate?

All clinical trials must:

- follow federal laws and ethical guidelines
- make sure potential participants understand the trial before they agree to be in it, which is called informed consent
- be approved by an expert group called an institutional review board, also called an IRB, that helps make sure the trial is fair and as safe as possible

You can talk to the trial staff or the IRB anytime you have concerns about being harmed.

What are some of the risks and benefits?

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

Every clinical trial is different and has different risks and benefits. Ask your doctor about how a trial may affect you. You may also want to discuss with your family members, trusted friends, or members of your faith community.

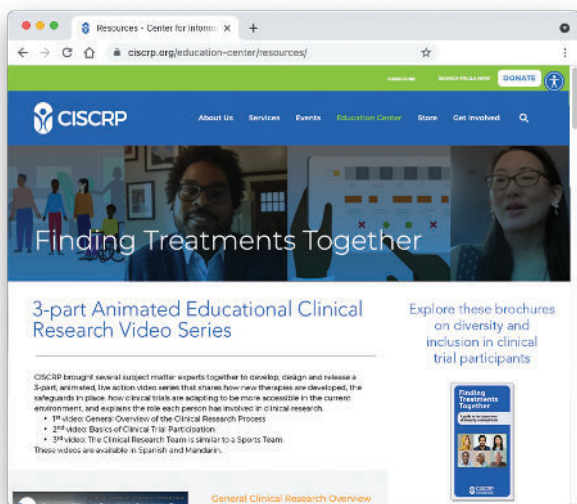
What are other ways you can get involved?

Joining a clinical trial is just one way you can have a positive impact on your community and help future generations. Here are other ways to get involved:

- 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.

How can you find more information?

Patient advocacy groups may be able to tell you about clinical trials for your condition. If you would like to learn more about current clinical trials, call **1-877-MED-HERO**.



Find more information about clinical research and the topics in this brochure on our webpage **“Finding Treatments Together”**

findingtreatmentstogether.org



This brochure was developed together with members of the Hispanic and Latino 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