

A Guide to Clinical Trials for Asian Communities

Finding Treatments Together



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 and 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 races, ethnicities, ages, genders, or sexes in different ways. It's important for everyone to be involved in clinical trials so we know how new treatments work and if they are safe for people from every community.

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People from Asian and Pacific Islander communities speak hundreds of languages and are from over 50 countries in East Asia, South Asia, Southwest Asia, South East Asia, and the Pacific Islands. Because of this diversity, some of the content in this brochure may not apply to you.



Why have people from Asian communities not been represented in clinical trials?

Language barriers

You have the right to communicate with the clinical trial staff in your preferred language. You can ask for an interpreter or request documents in the language of your choice. It is also okay to bring family members with you.

Cultural concerns

Some people avoid clinical trials due to cultural beliefs or fear of negative reactions from their community. While you should discuss your health with your family and people you trust, it is important to make the decision that is best for you.

Mistrust of clinical research and healthcare

Some people mistrust doctors, researchers, or the healthcare system, sometimes due to discrimination. Others have concerns that research will not benefit their community, or that their community will be misrepresented.

Changes in laws and guidelines have led researchers to work with communities and address the reasons for the lack of trust. For example, some researchers are making trial results easier to access and understand for participants and the public.



How are you protected if you participate?

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

- Follow laws and guidelines that make sure trials are ethical
- Include a process called informed consent to fully inform people about a trial before they can agree to be in it
- Be approved by an expert group called an institutional review board (IRB) that helps make sure the trial is as fair and as safe as possible

When you sign an **informed consent** form to participate in a trial, you are **not** signing your rights away. Being in a trial is optional. **You can stop at any time and for any reason.** The trial staff will help you do this safely.

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

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 to participate.

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 talk with your family members, trusted friends, or members of your faith community.

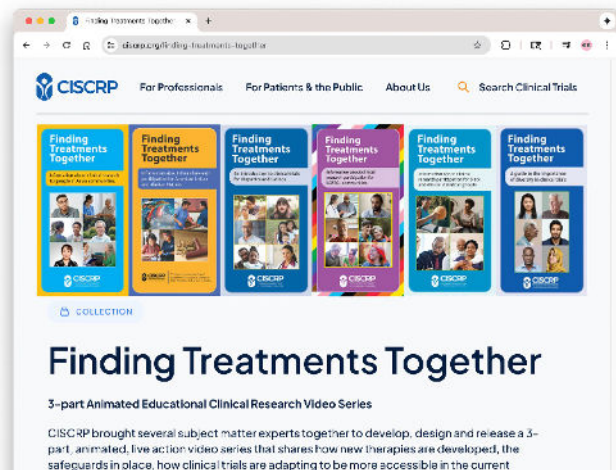
What are other ways you can get involved?

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 support 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**.



For more information on the topics in this brochure, and for translations of this brochure, go to:
findingtreatmentstogether.org



This brochure was co-developed together with a diverse group of people and experts who have experience working with diverse communities.

It was also reviewed and tested with patients, the public, and health professionals. They all helped to make sure it is clear, non-biased, and culturally appropriate.



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