A Guide to Clinical Trials for Native Hawaiians and Pacific Islanders

Finding Treatments Together



CISCRP
Center for Information & Study on Clinical Research Participation

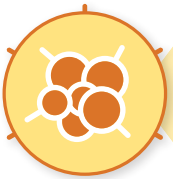
Why are clinical trials important?

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.

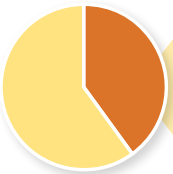
Why should clinical trials have diverse participants?

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.

Although Native Hawaiians and Pacific Islanders have shared ancestry, they include over 30 unique people groups with their own distinct cultures and practices. When more Native Hawaiians and Pacific Islanders participate in clinical trials, we can learn more about what treatments are best for people from each of these unique groups.



Among people ages 20 to 49, Native Hawaiians and Pacific Islanders are more likely to die from cancer than any other racial group.



6 out of every 10 drug trials did not document how many Native Hawaiian and Pacific Islander participants were included in their study.



For the drug trials that did report the number of Native Hawaiian and Pacific Islander participants, none of them reported having enough to properly represent the population of Native Hawaiians and Pacific Islanders in the U.S.

Sources: https://doi.org/10.1093/jnci/djad069
https://jamanetwork.com/journals/jamanetworkopen/fullarticle/2825439



Talk to your family, friends, and trusted community to help you decide if joining a clinical trial is right for you.

Why have Native Hawaiians and Pacific Islanders been underrepresented in clinical trials?

Impact of colonialism

Colonialism is when a country or group of people takes control of another country or region and takes advantage of its people and land. The effects of colonialism have negatively impacted the health and wellbeing of Native Hawaiians and Pacific Islanders for generations. Colonialism brought illness and disease that devastated people throughout Hawaii and the Pacific Islands. Today, issues like low income, homelessness, substance abuse, and heart disease in Native Hawaiian and other Pacific Island communities can all be traced back to colonialism.

One of the long-term effects of colonialism is mistrust of health professionals among Native Hawaiians and Pacific Islanders. Mistrust of doctors and researchers might make some people unlikely to participate in clinical trials. By acknowledging past abuses, researchers are taking steps to make sure that all people receive fair treatment.

Cultural concerns

People might have concerns that clinical trial participation will conflict with cultural or religious beliefs. Traditional Hawaiian healing practices focus on prayer, massage, and plant-based treatments. When doctors and researchers take the time to learn about and honor these traditional practices, they can combine them with Western medicine. You have the right to find clinical trials and healthcare that respect your beliefs, values, and traditional healing practices.

Access to the mainland

It may be difficult to make trial visits if you live on an island and the trial is happening on the mainland. In some trials, visits can take place over a phone or video call, or through local doctors and researchers. You can discuss these possibilities with your healthcare provider.

Lack of awareness

Native Hawaiians and Pacific Islanders are not always made aware of opportunities to participate in research. The research community is actively working toward increasing this awareness to better include Native Hawaiian and Pacific Islander participants in clinical trials.

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 makes sure the trial is as fair and as safe as possible.

Being in a trial is your choice

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.

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 treatment.
- You may have frequent testing or blood draws.
- You will need to set aside time for participation.

Possible benefits

- You may help researchers learn more about how treatment affects your community.
- You may have access to treatments for your condition before they are available to other patients.
- Your health will 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 and loved ones to decide if the trial is right for you.

What are other ways you can get involved?

Joining a clinical trial that tests a new treatment for an 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 with the condition that the treatment is intended to treat.
- Sit on a patient advisory board that helps ensure that trials have the participants' best interests in mind.
- Talk with your family and friends to raise awareness about clinical research in your community.

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.

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 our search clinical trial services, call **1-877-MED-HERO** or visit https://www.ciscrp.org/search-clinical-trials

For frequently asked questions (FAQs) about clinical trials, visit: ciscrp.org/faqs

For more information from CISCRP's *Finding Treatments Together* series and for translations of this brochure, go to: www.ciscrp.org/findingtreatmentstogether.

Land Acknowledgement

We recognize that the work of clinical research has an impact on indigenous land across the world, including within the Pacific Islands. We would like to acknowledge and pay respect to the traditional owners of these lands—past, present, and future.

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

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