

COMMON MYTHS ABOUT CLINICAL TRIALS



Information about the following topics:

- Study Trial Requirements and Informed Consent
- Clinical Trial Doctors and Your Health
- Costs and Expenses
- Placebos and the Study Drug

MYTH: IF I WANT TO JOIN A TRIAL, I WILL NOT BE TOLD ANYTHING ABOUT THE TRIAL OR TREATMENTS I MIGHT TAKE.

Fact: Researchers are not allowed to give you treatment in a trial unless you fully understand what is going to happen.

Before agreeing to be in a trial, the trial team will walk you through the process. You can ask questions about anything you want, like what treatment you might get, what happens during visits, what the potential risks and benefits are, and how long the trial might last. This process is called “informed consent.” Information about the trial will be provided in a printed or digital document, called an informed consent form.

You can take as much time as you need before deciding. It is very important to understand a clinical trial and to be comfortable with what is planned to happen before you agree to participate.

MYTH: I CAN JOIN ANY TRIAL.

Fact: Each clinical trial has a list of requirements about who can be in the trial. For example, the researchers might need people of a certain age, gender, or health condition. These requirements can be found in the informed consent form you will get before agreeing to join a trial. These requirements are in place to make sure each trial gets the most accurate results and is as safe as possible.

MYTH: TRIALS ARE DANGEROUS. AS A PARTICIPANT, I AM NOT PROTECTED.

Fact: While there are some risks, every clinical trial has a detailed plan reviewed by many experts to make sure it is as safe as possible. As a participant, you are protected from unnecessary risk.

The experts who review and approve trial plans are from federal health agencies and institutional review boards (IRB). An IRB is made up of doctors, scientists, and community members. These experts also monitor the trial while it is happening and can stop the trial if they think it is unsafe.

The experts will not approve the trial plan if the potential risks to a participant are too much. The potential risks for every trial are different. There may be discomfort, pain, and medical problems that cause lasting health issues or death.

All the potential risks must be explained to you before you agree to be in a trial. Doctors will monitor your health throughout a trial, and you can leave a trial at any time for any reason.

MYTH: IF THERE IS A CLINICAL TRIAL THAT COULD HELP ME, MY DOCTOR WILL TELL ME ABOUT IT.

Fact: Your doctor may not know about all available clinical trials. Patient advocacy groups can help you find trials and provide resources to help you decide if you should participate.

There are many companies that can help you find trials, and you can also search for trials online. The National Institutes of Health has a website you can search to find trials: www.clinicaltrials.gov. Many research companies also have websites that list their own trials.

You should always discuss any clinical trial with your doctor to help you decide if it is a good choice for you.

MYTH: BEING IN A CLINICAL TRIAL WILL NOT HELP ME.

Fact: If you have a disease or condition, the treatment and care you get in a trial may improve your disease or condition or make you feel better. Many clinical trials use new treatments that are not available to the public. Some of these treatments may help you more than anything currently available.

But, it is always possible that the treatment might not work, or you might get a placebo, which does not have any medicine in it.

MYTH: BEING IN A CLINICAL TRIAL COSTS A LOT AND IS NOT COVERED BY MY INSURANCE.

Fact: There are often no costs to you for being in a trial. You might have trial-related expenses such as travel, parking, hotel, or childcare. But, the researchers usually reimburse these expenses.

Before you agree to be in a trial, it is important to speak with the trial team and your insurance company about any costs you may have to cover.

GENERAL RESOURCES

CISCRP's Education Center

You may have other questions about the topics in this brochure, or about clinical research in general.

CISCRP's website has videos, brochures, FAQs, Questions to Ask, and other resources to help you learn more.

www.CISCRP.org/education-center

1-877 MED HERO

MYTH: I MIGHT BE GIVEN A PLACEBO WITHOUT MY CONSENT INSTEAD OF MEDICINE I NEED.

Fact: Before agreeing to be in a trial, you are told if you might receive a placebo. A placebo looks like a treatment, but does not have any medicine in it. Researchers use placebos to help make sure any changes in the participants' health are actually caused by the trial treatment.

You do not get to choose if you get the trial treatment or the placebo, and you may not know if you get the placebo until after the trial. If you need medical treatment and your trial includes a placebo, the placebo would be given in addition to standard medical treatment.

Not all trials use a placebo. If there is a chance you may get a placebo and you do not want it, you do not have to join that trial.

Search Clinical Trials

If you are ready to find trials in your area, CISCRP's free service will provide you a list of relevant trials for discussion with your trusted doctors, family, and friends.

searchclinicaltrials.org

1-877 MED HERO

ClinicalTrials.gov

Available in both English & Spanish, this website is run by the National Institutes of Health. It provides education about clinical trials and lists many of the trials taking place in the United States.

www.clinicaltrials.gov

1-800-411-1222

The information on this webpage is drawn from an educational brochure that was reviewed by a panel of patients, professionals, and members of the public.

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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