MYTH

Trial volunteers are guinea pigs.

FACT

Every trial has an informed consent. This document includes all of the information needed to help make a decision on taking part in the trial. It includes the purpose of the trial, tells about all of the visits and activities to be done, and includes possible risks and benefits. This information can help you decide about joining the trial.

If you are thinking about being in a trial and have questions about these items or others, ask.

If you are thinking about participating in a clinical trial and have additional questions, you should talk to your doctor or a patient advocacy organization for your disease or condition.

Visit CISCRP for more information including disease and condition specific resources.

EDUCATION before PARTICIPATION

"DEBUNKING COMMON MYTHS" is part of CISCRP's Education Before Participation resource series.

REVIEWED AND APPROVED BY A CISCRP EDITORIAL PANEL

An editorial panel of patients, public and professional representatives has reviewed this educational brochure.

CISCRP
THE CENTER FOR INFORMATION & STUDY ON CLINICAL RESEARCH PARTICIPATION

CISCRP is an independent non-profit organization dedicated to engaging the public and patients as partners in the clinical research process through education and outreach programs. CISCRP services also assist clinical research stakeholders in understanding public and patient attitudes and experiences in research to improve patient satisfaction. CISCRP is not involved in recruiting patients for clinical trials, nor is it involved in conducting clinical trials.

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DEBUNKING COMMON MYTHS ABOUT CLINICAL TRIALS (STUDIES)

MYTH

Some people who try to volunteer for a clinical trial are told by the research team that they are not allowed to be in the trial. The process seems unfair.

FACT

Clinical trials always have a list of rules (such as age, sex, what health conditions you cannot have) that must be met for someone to be in the trial. These rules are to protect volunteers and to help researchers understand if the effects they see are caused by the trial medicine. People who do not meet these rules cannot take part. The rules are different for each trial, and are listed in the informed consent document.

MYTH

The trial may include painful or unpleasant parts.

FACT

The activities are different for each clinical trial. The doctor will talk to you about this, and the activities are always listed in the informed consent document. The IRB checks to see that the benefits and risks are carefully weighed and that the trial is reviewed for unnecessary harm/discomfort before it starts.

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. The National Institute of Health has an online database that you can search to find appropriate trials: www.clinicaltrials.gov. Unfortunately, using that database requires quite a bit of time, so it's worth making contact with a patient advocacy group. Many of them have tailored services that can help you with your search. Once you have information about clinical trials, speak with your doctor about participating.

CISCRP has a free service called Search Clinical Trials. CISCRP staff will help you find clinical trials that are relevant to your needs. Visit **www.searchclinicaltrials.org** or call **1-877-633-4376**.

MYTH

Clinical trials are dangerous because they use new practices and medicines.

FACT

Keeping trial volunteers safe is the top priority. All clinical trials are reviewed before they start by the Food and Drug Administration (FDA) and an institutional review board (IRB), made up of doctors, scientists, and community members, whose main purpose is to decide if the trial is safe to do. People in a trial are closely watched, and the treatments they receive have gone through a rigorous testing process before being given to people.

MYTH

If I join a clinical trial, I might get a "sugar pill" or placebo instead of a real drug.

FACT

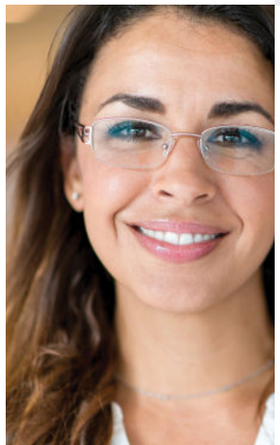
A placebo is a sugar pill that does not cause harm or good. The decision about whether to use a placebo in a clinical trial is based on how serious the illness is, whether an existing treatment is available, and other considerations that ensure a high standard of ethics. In trials where a treatment is already available for the disease or condition, or in the case of serious illness, the available treatment is usually used instead of a placebo. In other trials, one group gets the new treatment while another group gets placebo. This is done so that the new treatment can be compared with no treatment in similar people.

MYTH

If I join a clinical trial, I won't get the same level of care that I receive with my doctor.

FACT

The care people get in a clinical trial is usually excellent. People in trials often say that the trial doctor and staff watch them more closely than their own doctor or nurse does during a regular office visit. This is because trials have very detailed procedures and often include extra tests and extra visits.



MYTH

Being in a clinical trial does not help the volunteer.

FACT

Being in a clinical trial may improve your medical condition. You may also get extra tests, lab work, and monitoring that you might not otherwise have, as well as having the opportunity to receive a drug that would not otherwise be available to you. Trial volunteers also play a key role in helping scientists find new treatments that will help people live longer and have better lives.

MYTH

Being in a clinical trial costs a lot and isn't covered by medical insurance.

FACT

Many insurance companies pay for costs that are not covered by the research sponsors doing the clinical trials, especially the costs for routine care and normal activities that would be done even if you were not in the trial. Trial subjects rarely have to pay any trial costs. Sometimes volunteers are paid back for expenses they might have, such as transportation and parking.

MYTH

Clinical trial volunteers need to sign an informed consent form that doesn't let them stop before the trial is over.

FACT

The purpose of informed consent is to protect the rights of people taking part in clinical trials. It tells you all about the trial, including activities, visits, and potential risks and benefits. You may leave the trial at any time, but should always let the clinical trial team know first, because some medicines should not be stopped without the doctor's help.