Myths & Facts

Source: Debunking Common Myths About Clinical Trials. PhRMA/Center for Information & Study on Clinical Research Participation

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MYTH: Clinical trial volunteers are merely human guinea pigs.

FACT: Strict guidelines are in place to ensure that you and all other clinical trial volunteers are treated fairly and ethically. Before an investigational drug can be given to people who volunteer to participate in clinical trials, scientists must complete a rigorous screening and preclinical testing process, and all participants must undergo a thorough informed consent procedure to understand their rights.

MYTH: Informed consent is just reading and signing a piece of paper.

FACT: There are two principal components of informed consent: an informed consent document includes all the information you will need to help make a decision about taking part in the clinical trial; the informed consent process provides you with ongoing explanations that will help you make educated decisions about whether to begin or continue participating in a trial. Thus, informed consent is an ongoing, interactive discussion, rather than a one-time informational session.

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

FACT: 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. If you have a serious or life-threatening disease, the best available treatment (called "standard of care) will be used instead of a placebo.

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

FACT: Because clinical trials are designed for research purposes, some level of risk is involved. However, clinical trial participants receive investigational drugs only after they have gone through a testing process that indicates that the drug is likely to be safe and effective for use in humans. Participant safety is a top priority and is frequently and rigorously assessed by researchers for the duration of the trial.

MYTH: Once I decide to participate in a clinical trial, I will not be able to change my mind.

FACT: Clinical trials rely on voluntary participation. You are free to leave a clinical trial at any time, even after you have signed an informed consent and received the investigational drug or placebo. However, you should always let the clinical trial team know before you decide to leave the trial because some medicines cannot be stopped safely without a doctor's help.

MYTH: I know someone who tried to volunteer for a clinical trial and was told by the research team that they are not eligible to be in the trial. The process seems unfair.

FACT: The protocol for a clinical trial includes eligibility criteria for who can and cannot take part in the trial. These guidelines are used to identify the people most likely to benefit from the clinical trial and to help ensure that researchers will be able to conduct a thorough investigation of the drug. It is important to note that eligibility criteria are not used to reject you personally. Some eligibility criteria include age group, gender, having a certain type or stage of cancer, having received (or not received) certain medicines in the past, medical history and current health status

MYTH: Being in a clinical trial won't help me.

FACT: If you choose to participate, you may have the opportunity to receive an investigational drug that is not available to people outside the trial. And, your clinical trial research team will watch you closely and may provide you opportunities for additional tests and lab work that might not be part of your usual care. According to CISCRP's 2013 Perceptions and Insights study, some trial volunteers also report great personal satisfaction in the fact that they have played a key role in advancing medical science that will help more people live longer, better lives.

MYTH: Being in a clinical trial is expensive and isn't covered by my medical insurance.

FACT: Volunteers for clinical trials rarely have to pay any costs related to participating in the trial. There are two types of costs directly associated with a clinical trial: research costs and patient care costs. Research costs are usually covered by the sponsoring organization, and patient care costs are covered by many health insurance carriers. You should ask the clinical trial research team which costs will be your responsibility and also check with your health insurance carrier about the coverage they provide for clinical trial participants before making the decision about participating in a clinical trial.

MYTH: If there is a clinical trial that might help me, my doctor will tell me about it.

FACT: The National Institutes of Health has an online database that you, your family or doctor can search to find appropriate trials: clinicaltrials.gov. Alternatively, it's often worth making contact with a patient advocacy organization to help you navigate the process.