

To report a complaint, concern, or violation visit oprs.usc.edu/complaints

You can also contact the offices listed below.

Office for the Protection of Research Subjects (OPRS)

3720 South Flower Street 325
Los Angeles, CA 90089
(213)-821-1154
oprs@usc.edu

Health Sciences Institutional Review Board

General Hospital, Suite 4700
1200 North State Street
Los Angeles, CA 90033
(323)-223-2340
irb@usc.edu
oprs.usc.edu/hsirb

University Park Institutional Review Board

Credit Union Building (CUB), Suite 301
3720 S. Flower Street
Los Angeles, CA 90089
(213)-821-5272
upirb@usc.edu
oprs.usc.edu/upirb

For copies of this brochure contact

oprs@usc.edu

Adapted from the Department of Veterans Affairs' Office of Research Compliance & Assurance "I'm a veteran. Should I participate in research?", and the University of Iowa Human Subjects Office "So you're thinking about being in a research study."

<http://research.uiowa.edu/hso/docs/brochureforpublic.pdf>

Should I participate in research?



What to ask before deciding to participate in research...



What is research?

Research is collecting and studying information to answer a question. Other words for research are clinical trial, protocol, survey, or experiment.

What is a human subject?

A subject is a person who volunteers to participate in research.

Who can be a subject in a research study?

Most research studies have requirements that must be met for a subject to participate. These requirements ensure safety and usefulness of the research. Some studies have age requirements such as being over 18. Other studies have a more focused requirement such as having a certain disease.



Do I have to participate?

NO! Participating in a research study is voluntary. A subject can drop out of a study at any time. Refusing to participate in a study will not result in a penalty or loss of any benefits to which the subject is entitled.

Are there risks to being in a research study?

Research may involve different types of risk. A study that asks you to fill out a survey has only minor risks, such as questions that may make you uneasy. For other studies, such as taking an experimental drug, the risks can be greater (e.g. having a bad reaction to the drug). The research team is required to explain the foreseeable risks of being in the study before deciding whether or not to participate.

Are there benefits to being in a research study?

Not everyone who participates in a research study will benefit personally. Sometimes, participating in a research study will benefit society by helping people learn about a certain disease or condition. In some studies, subjects may personally benefit from medication or counseling that aids health.

Who leads a research study?

The Principal Investigator (PI) leads the research study. The PI is responsible for the overall conduct of the research study. The PI is also responsible for the safety of the subjects. PI's are often doctors, faculty, or staff.

Who else is involved in research studies?

Principal Investigators often have a research team to assist them in their study. The research team can include research assistants, research nurses, data coordinators, statisticians, and other people with special skills needed for the study.

Who reviews a study?

At USC, all studies with human subjects are reviewed by an Institutional Review Board (IRB) before they are allowed to begin.

What is an IRB?

The IRB's committee is charged with protecting the rights and welfare of the subjects in a study. An IRB is composed of scientists and non-scientists who review projects submitted by researchers. The University of Southern California has four IRBs; one on the University Park Campus, and three on the Health Sciences Campus.

Who will see my records?

The information in your research record will be confidential. Information will only be given to researchers who carry out the study or to those who make sure the study is safe and carried out the way it was planned.



Are there any special rules to help protect certain subjects?

Children, pregnant women, and prisoners can all be participants in research studies, but are considered potentially "vulnerable populations." There are special rules to protect participants who are in one of these groups.

What kinds of procedures are involved?

Research studies can involve a variety of activities, from filling out surveys and questionnaires to taking experimental medicines or using experimental devices. Some research studies last only a few minutes, while others last for several years. The research team will describe all the research activities before you agree to be in the study.

What is informed consent?

Informed consent is the process of learning the key facts about a research study before you decide whether or not to participate. Your participation should be based on a clear understanding of what will take place in the study and how it might affect you. The consent process begins when the research staff explains to you the facts about the study. The research staff will assist you with the "informed consent form" that has these facts so you can decide whether or not you want to take part in the study. These facts include details about the study, tests, or procedures, and the benefits and risks that could result. Alternatives to participating will be discussed should you decide not to participate, and as your will rights as a research volunteer.

What questions should I ask before I agree to take part in a research study?

Before you decide to participate in a research study, you need to know as much as possible about it. If you have any concerns, be sure to ask questions. The following is a list of important questions.

Not every question applies to every study. You have every right to get answers.

- Will I benefit from this study?
- What is the main purpose of this study?
- Will this research help me to understand my condition? If so, how?
- Will I be able to see my own doctor?
- What alternatives are available if I decide not to participate in the study?
- Is it possible that I will receive only a placebo (inactive substance)?
- What risks are involved in this study?
- How long is the study going to last and what will I be asked to do as a participant?
- What will happen to specimens I give?
- Who has reviewed/approved this study?
- If I have a condition, could it get worse during the study?
- Do I have to pay for any part of this study?
- Will I be paid to be in this study?
- If I decide to participate in this study, how will it affect my daily life?
- Will I receive any follow-up care after the study has ended?
- Will I be told the results of the study?
- Can anyone find out whether I'm participating in the study?
- How do I end my participation in this study if I change my mind?
- Whom do I contact for questions and information about the study?
- If the treatment works for me, can I keep using it after the study?



Where can I find health and research information?

USC Human Subjects Information

<http://oprs.usc.edu/about/being-a-participant-in-research/>

ClinicalTrials.Gov

Info about federally and privately funded research: www.clinicaltrials.gov

CenterWatch

Database of industry-sponsored international clinical trials: www.centerwatch.com

Family Doctor

Health info from the American Academy of Family Physicians: www.familydoctor.org

Healthfinder

A health library available in English and Spanish: www.healthfinder.gov

Medline Plus

The National Library of Medicine's complete health info portal: <http://medlineplus.gov>

National Cancer Institute

Clinical details about every type of cancer and the latest treatments: www.cancer.gov