RESEARCH PARTICIPANT BROCHURE

What is behavioral or social science research?

The purpose of a research study is to try to learn. There are many different kinds of research studies in the social science field. Some studies involve taking a survey on the internet or being interviewed in a public place. Some research studies are conducted to help researchers find better ways to resolve a need in the community, or to learn whether a type of parenting helps children to behave better. The study purpose might even be to better understand how people feel about a certain topic or problem in order to help find a solution.

How will I find out about social science research studies?

There are many ways to become involved in a research study. You may see or hear an advertisement asking for research participants. You may be asked because you live in a particular area or have a particular condition. If you are thinking about being in a research study, you should learn about it so you can make an informed decision about whether you want to participate.

Should you be in a research study?

That is entirely up to you. You should not feel pressured into participating in research.

Who is in charge of a research study?

The person who is in charge of a research study is called a Principal Investigator or PI. Sometimes the PI has a study coordinator who helps with the project. The PI or another member of the study staff will tell you about the study. You can ask any questions you want. Find out all you can. Their job is to give you enough information so you can decide whether you want to be in the study. The study staff will discuss the study with you. Telling you all about the study is called the informed consent process. It is the PI's responsibility to provide you the

information that you need to make the choice that is right for you.

What information do I need to know about a research study?

You should always ask questions before deciding to become a volunteer for a study. This will allow you to find out the information needed to make a wise decision. If the information is not clear, make sure to ask the researcher to explain the information in a different way.

The informed consent process helps you understand and learn key facts about a research study. Some of the key facts to learn about are the purpose of the research, the procedures involved, any benefits, any risks, and your rights as a volunteer. Your agreement should be based on your understanding of what will take place in the research and how it will affect you.

The informed consent process will tell you about any potential benefits to you or to other people. It will also tell you about any known risks or inconveniences that may occur if you take part in the study. Risks in social science and behavioral studies could include things like feeling uncomfortable answering survey questions or embarrassment from someone learning things about you that you didn't want to be known. Some studies have almost no risk at all, such as when questions on a survey ask about favorite foods or activities. It is important to understand any risks of the study, how likely they are to occur and whether you will still want to participate knowing those risks exist.

The informed consent process will tell you what you can expect to happen and how much time the study will take. Another very important thing to know about is who will be able to see information about you.

You will also be provided contact information if you have any problems or questions while you are in the study or afterward. This includes contact information for the Institutional Review Board (IRB) who approved the study.

Sometimes the informed consent process includes a piece of paper or set of

papers called an Informed Consent Document or ICD. In most cases, you will be asked to sign an ICD if you agree to be in the study, but sometimes you will just be provided information and not have to sign a form. Remember the ICD is not a contract. Even if you sign it, you can stop anytime. You don't even have to begin the study if you change your mind.

The informed consent process continues throughout the study. If you join a study, you can ask questions at any time during the study. If new information is discovered that might make you reconsider whether you want to be in the study, the study staff will tell you about this new information. Then you can decide whether or not you want to continue being in the study.

Do I have to be in a study if I don't want to?

It is completely up to you to decide whether you want to be in a research study. If you don't want to participate, just tell the people who are asking that you don't want to participate. If you do decide to participate, but change your mind later, that is fine. You can stop participating whenever you want.

What is an IRB?

An Institutional Review Board (IRB) is a group of people, such as scientists, doctors, college faculty, staff, and other people from the local community. The IRB makes sure that research is well-planned and ethical. IRBs review research studies to make sure that there is the least possible risk to volunteers and that people are chosen fairly.

Why Should Minorities and Women Participate In Clinical Trials?

In the past, most research has been done on white men. This means there is not much information about some groups, such as African Americans, Hispanic Americans, American Indians, Asian Americans, and women.

How can I learn about the results of research?

The study staff that tells you about your rights as you are deciding whether or not to participate in the study will also let you know when results may be available. Ask how you will get this information. If you have questions about the results when you receive them, ask the researcher who can help you to understand what they mean.

It often takes years before the results of a study are available. This is because of the time it takes to conduct the study, including getting enough people in the study to make the results meaningful.

What if I need further information?

You may contact the Office for the Protection of Human Research Subjects (OPHRS) at East Tennessee State University to discuss concerns, obtain information, or offer input.

Institutional Review Board (IRB) Staff

https://www.etsu.edu/irb/contactus.php

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