

## **Should I take part in a research study?** *Here are some things you should know*

### ***What is an IRB?***

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The Institutional Review Board (IRB) is a group of people with varying backgrounds that review and approve research involving human participants to ensure participants are treated ethically. The IRB includes scientists, non-scientists, and people from the community. The IRB serves to protect rights and welfare of research participants before and during the research study. For example, the IRB makes sure that any risks are as small as possible and that any benefit outweighs any risk. The IRB does not decide for you whether or not you take part in the research study. The IRB decides whether it is right to ask people whether they want to take part in a particular research study. The IRB also reviews studies after they are approved to make sure participants are protected.

### ***Should I take part in a research study?***

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Many research studies are conducted each year. These studies have contributed to physical and mental health improvements for many people. You may be asked to volunteer for a research study approved by the ASU IRB. This pamphlet aims to help you understand your rights as a research study volunteer. It will help you to decide if you should take part in a research study. We urge you to review this information and discuss it with other people you trust.

### ***Who will see my records?***

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Like your medical record, the information in your research study record will be confidential. Information will be given only to the people who need it. This includes researchers and staff who carry out the research study. This may include the Institutional Review Board (IRB), the company or group funding the research study, or various government oversight agencies. It is important for these groups to be able to look at your records, so they can ensure that the research study is conducted using acceptable research practices.

### ***What is a research study?***

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A research study is an organized activity to learn more about a problem or answer questions. Researchers conduct many different kinds of studies. For example, a research study may test if a treatment is safe and effective. A research study may be done to find out what health care practices work best. A research study may use a survey or an interview to understand feelings people have about their behavior.

### ***Who will answer my questions?***

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The research team will explain the research study to you. The consent form includes this explanation. You should take your time when you read the consent form.

If you have any questions, ask the research staff. If you don't understand something, ask them to explain it to you so you do understand. The information will be given to you in a language that you know. If English isn't your native language, ask if there is someone who can explain the study to you. You can take the information home. You can discuss it with your family, friends, a health care provider, or others before you decide whether or not to take part in the research study. If you decide to take part in the research study, you will be asked to review the consent form.

The informed consent process is more than just reviewing a piece of paper. It is a process that goes on throughout the research study. During the research study, you may be told of new findings, benefits or risks. At that time, you can decide whether or not to continue to take part in the research study. You may decide not to take part. You may change your mind and leave the research study before it starts. You may also leave at any time during the research study or the follow-up period without penalty.

### ***Why should I volunteer for a research study?***

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There are many reasons to participate in research study.

You may want to:

- Help people who are sick
- Help the university community
- Help scientists find out more about how the human body and mind work
- Take part in a research study that is trying to find a better treatment for a condition that you have

If you decide to take part in a research study, you do so as a VOLUNTEER. That means YOU decide whether or not you will take part. If you choose to do so, you have many important rights.

### ***What is informed consent?***

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Informed consent is the process of learning the key facts about a research study before you decide whether or not to volunteer. Your agreement to volunteer should be based upon knowing what will take place in the research study and how it might affect you. Informed consent begins when the research staff explains the facts to you about the research study.

The research staff will assist you with the "informed consent form" that goes over these facts so you can decide whether or not you want to take part in the research study. These facts include details about the research study, tests or procedures you may receive, the benefits and risks that could result, and your rights as a research volunteer.

### ***Are there benefits to being in a research study?***

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There may or may not be a direct benefit to you if you take part in a research study. For example, your health or a health condition you have may get better as a result of your participation in the research study.

It may stay the same. It may get worse. No one can predict what will happen with a research study or how it might affect you. The research study may not help you personally. The research study may result in information that will help others in the future.

### ***Are there risks or side effects in a research study?***

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Sometimes research procedures and treatments may cause discomfort and bad side effects. The questions being asked could make you uncomfortable. The risks of the research study may not be known completely when you start the research study. The research staff will discuss with you known possible risks so you can decide if you want to volunteer. If you do volunteer, the research staff will tell you about any new risks that they learn about during the research study for as long as you take part in the research study.

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

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Before you decide to volunteer to take part in a research study, you need to know as much as possible about the research study. If there are any issues that concern you, be sure to ask questions. You might want to write your questions down in advance or take this booklet with you. The following is a list of sample questions. Not every question will apply to every research study.

- Who is doing this research study and what question might it answer?
- Will this research study help in understanding my condition? If so, how?
- What will participation entail?
- Will I have to make extra trips?
- What could happen to me, good and bad, if I take part in the research study?
- How long will this research study last?
- What will happen to any specimens that I give?
- Who has reviewed and approved this research study?
- What other options or choices do I have if I decide not to take part in this research study?
- Will I be charged anything or paid anything to be in this research study?
- If I decide to participate in this research study, how will it affect my daily life?
- What will happen to me at the end of the research study?
- Will I be told the results of the research study?
- Who will find out that I am taking part in this research study?
- How do I end my participation in this research study if I change my mind?
- Whom do I contact for questions and information about the research study?

Remember, if you do not understand the answer to any of your questions, ask again. Ask the person to explain the answer in a way you can understand it. If you forget the answers to the questions during the research study, just ask them again.

## ***What if I do not want to take part in a research study?***

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If anyone asks you to take part in a research study, you have the right and are free to say "no."

### **Remember:**

- Your decision will not affect how you are treated or your grades at ASU.
- You need to weigh both the risks of the research study and the benefits.
- It may be helpful to talk with family members, friends, or your health care providers.
- If you decide to volunteer for a research study, you can change your mind and stop or leave the research study at any time. Your decision will not affect how we treat you.

## ***Whom can I contact for more information?***

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If you have questions about research at Arizona State University, please contact the resources listed below:

Susan Metosky, IRB Administrator

(480) 727-0871

[susan.metosky@asu.edu](mailto:susan.metosky@asu.edu)

*Please call this number if you have concerns or complaints, or want to talk to someone about research at this organization.*

Office of Research Integrity and Assurance

660 S. Mill Avenue, Tempe, AZ 85287-6111

(480) 965-6788

[research.integrity@asu.edu](mailto:research.integrity@asu.edu)

*The ASU IRB thanks the Pennsylvania State University IRB for sharing their brochure which has been modified for ASU.*