Happy Birthday! You are now a legal adult. Learn about your rights and options in clinical research.

What happened when I started clinical research?
Your parent/guardian gave permission for you to be in the clinical research. Their permission was called consent. You may have been asked for your agreement to take part in the research too. Your agreement was called assent.

Why would I say YES to being in clinical research?
Some clinical research test experimental treatments or procedures. By participating, you may be helping others in the future!

Why would I say NO to being in clinical research?
First, there may be risks. Second, some treatments may not help you. Third, you may have other options that you prefer. If you are unsure, ask your doctor any questions.

What happens when I become a “legal adult”?
You make your own decisions. If you are already participating in research, you will be asked if you want to continue. This is called consent.

How is consent given?

STEP 1
Your doctor will explain how the research works
You may ask any questions

STEP 2
Sign the informed consent document
Just say you want to participate

How is consent different from assent?
Both consent and assent mean agreement. But only legal adults can give consent.

Make sure you understand everything before giving consent. Ask questions!
**Assent**: The agreement to participate in research by someone too young to give consent.

**Consent**: The agreement to participate in research by someone who is a legal adult.

**Clinical Research**: Tests new medical treatments on a group of people. Research tries to understand what makes people sick and what keeps them healthy.

**Informed Consent Document**: A form that describes the research, its risks, and its benefits. This helps people decide if they want to participate.

**Legal adult**: The age when a person is legally responsible for their own actions.

*Different countries and states have different ages of consent. For example, the age of consent is usually (but not always) 18 in the United States and 16 in the United Kingdom.

**Sample**: Something collected during research. This might be a small amount of your blood or other body fluids.

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**KNOW YOUR RIGHTS**

- To be treated with respect and care.
- To understand what the study is about and what will happen if you join.
- To understand all study forms.
- To be told about any benefits and risks of the study.
- To be told about other options instead of being in the study.
- To ask any questions you have.
- To choose whether or not to join the study: “No thanks, it’s not for me.” or “Yes, I’ll be in the study”.
- To get a copy of the consent form if you say yes.
- To change your mind after the study starts.

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**PRIVACY**

**How is my information kept private?**

There are many ways that your information is kept private. Ask your doctor how your privacy is protected.

**What happens to the information that was already collected?**

Generally, the information that has already been collected may still be used in the research.

**What happens to the samples that were already collected?**

It depends! Ask your doctor.

**Will people know that the samples are mine?**

It depends on how the samples were stored—they may be or may not identify you. The informed consent document should tell you what will happen to your samples once the research is over. If you’re not sure, ask!

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**www.iccanresearch.org**

**ICAN Approved**