

Participating in research is a choice

Joining a research study is an important personal decision. Before you join, researchers will talk with you about the goals of the study, and possible risks and benefits. They will also explain the rules they follow to protect your safety and privacy. Ask for help if you don't understand something or have questions.

You should never feel rushed or pressured to make a decision. Being part of a research study is completely voluntary – it's your choice.

After you understand the study, you can agree to take part by signing a document called an "informed consent form." You can change your mind at any time, for any reason, even after you sign.

Learning the results of research

Sometimes researchers who use your samples or information may share what they've learned with you.

Researchers might also learn information that could affect your health or the health of a family member. But, they might not know your identity or have your contact information. Some biobanks do keep a link to your identity, so they can contact you with information like this.

If learning the results of research on your samples is an option, you will have the chance to choose if you want to learn the results or not.

To learn more about this topic, see our [Incidental Findings in Health Research](https://catalyst.harvard.edu/incidentalfind.pdf) brochure at: catalyst.harvard.edu/incidentalfind.pdf

Questions to ask

You have the right to ask questions about research. Below is a list of questions you might want to ask before you agree to give samples or information for research.

- > How will you collect my sample or information?
- > What kinds of information will you store and share?
- > Who owns the biobank or is responsible for it?
- > Who will see my sample or information?
- > How will you protect my privacy?
- > How will researchers use my sample?
- > What types of research using my sample might be done in the future?
- > Will my sample or information be used for commercial purposes, such as developing a product for sale?
- > Will I learn the results of research on my sample?
- > Will you tell me about results that might affect my health or a member of my family's health?
- > Can I take my samples out of the biobank later?

If you have any concerns about how researchers will use your samples or information, please ask the researcher or your health care provider.



GIVING SAMPLES AND INFORMATION FOR RESEARCH



Participating in research is your choice.
Be informed. Ask questions. Get answers.

Researchers often study samples from the human body (such as a small amount of blood, tissue, or urine) to learn more about how the body works. Whether you are healthy or getting medical treatment, researchers might ask you to give a sample or information they can use in future research.

Questions? Call us at



This brochure contains general information for educational purposes and is not intended to provide medical advice. Talk with your own doctor or the research team for advice about your personal situation and health concerns.

Giving samples for research

You can choose to give a sample if researchers ask you to. Sometimes, a sample might come from a medical procedure you have, such as surgery or a blood test.

If you agree to give a sample, a researcher will talk with you about how it will be stored and kept secure. You will also sign a form that shows you agree to have your samples used in research.

Researchers might ask if they can share information from their research on your sample. They might share this information with researchers across the nation or even around the world.

Why researchers use samples

Researchers study human samples to learn about:

- > How the body works
- > How disease develops and affects the body
- > How to treat diseases and conditions – research on human samples is one way to find better treatments

Researchers call samples of blood, tissue, and other materials “biospecimens.”

Different types of biospecimens

Examples of biospecimens include:

- > Blood and parts of blood, such as plasma or red blood cells
- > Cells or tissues from the human body
- > Products the body makes, such as hair, urine, saliva, or sweat

Researchers also call biospecimens “biosamples.” So you might hear the terms “biospecimen,” “biosample,” or just “sample.”

What is a biobank?

A biobank is a place that collects and stores biospecimens. Just like a library has books, a biobank has samples researchers can study. A biobank is also called a “biorepository” or tissue repository. You might hear researchers use all these terms.

A biobank might also collect information about you.

This information might include:

- > Medical information
- > Genetic information
- > Information about you, such as your age, job, address, and more
- > Personal information, such as details about your lifestyle or where you live

This information might be linked to your samples.

Biobanks have rules for:

- > How you and other donors give samples
- > How they keep samples and information private
- > How they make sure only qualified researchers can use your samples or information
- > What happens if you decide to take your sample out of the biobank



Different types of biobanks

Some biobanks collect samples and information on just one disease or condition. Others collect many types of samples that can be used for different kinds of research.

Some biobanks have samples or information from just one laboratory or hospital. Other biobanks have samples and information from across the country (or outside the country), or from many different research studies. Some countries have government-funded biobanks, such as the National Cancer Institute in the United States.

Benefits and risks

You do not usually benefit directly from giving samples or information to a biobank, but doing these things could help others in the future. Letting researchers use your samples and information may help them develop new medical treatments.

A main risk of giving samples or sharing information is that your information could be accidentally shared with people who should not see it. Each biobank works hard to protect against this.

Considerations

If you give samples or information to a biobank, you usually have little or no control over how researchers use them in the future. But you can sometimes remove your samples from a biobank if you ask.

A new drug or treatment could be developed based on your and other people’s samples and information. If this happens, you will not be paid and do not receive any profits from that drug or treatment.