

National Cancer Institute

How You Can Help Medical Research



Donating Your Blood, Tissue, and Other Samples

U.S. DEPARTMENT
OF HEALTH AND
HUMAN SERVICES

National Institutes
of Health

You have the choice to donate samples, such as blood and tissue, for medical research. Medical researchers use samples to find new and better treatments for patients. Before you make your decision about donating, it is important that you understand what donation is, how it works, and how your consent plays a role.



People from all backgrounds and communities donate samples

What Are Samples?

Samples (also called *biospecimens*) include materials from your body such as tissue, blood, skin, hair, saliva, and urine.

Who Donates?

People from all backgrounds and communities donate samples.

Why Should I Donate?

Researchers use your samples, along with samples from thousands of other patients, to look for ways to prevent, find, or treat health problems like diabetes, heart disease, and cancer. Donating is a way that some patients cope with their disease. It also helps some families cope with the challenge of having a loved one who is sick. Many people find comfort knowing that by donating samples, they will help researchers make discoveries that can advance medicine and improve the treatment of others in their community.

How Do I Donate?

Ask your doctor or nurse what samples you may be able to donate. There are two ways you can donate.

- You may choose to **donate samples that are collected during a medical procedure**. Often parts of your samples remain after your doctor uses what he or she needs for medical tests. These samples are usually destroyed. But if you give consent, samples that aren't needed for your medical care can be used for research. You will not need to have an additional procedure for this type of donation.
- Or, you may choose to **donate samples through a procedure that is not related to your medical care**, such as a blood draw or saliva swab, for research purposes only.

Where Can I Donate?

Talk to your doctor or nurse to find out where you can donate your sample for medical research.

What Happens After I Donate My Sample?

If your samples are collected as part of your medical procedure, your doctor will first complete all your medical tests. With your consent, any extra samples may be sent to a *biobank*, along with some information about your general health.

A *biobank* is a place where samples are stored until they are needed for research. There are thousands of biobanks in the United States.

Researchers studied thousands of breast cancer samples. This helped them:

- Find out that 1 in 4 breast cancers carried extra copies of a certain gene
- Create a test to identify breast cancers that carried the extra gene copies
- Develop treatments that helped women with these types of breast cancers live longer

This was only possible because thousands of women gave their samples for research.



Questions and Concerns

- **Do I get to choose how my samples and information are used?**

No. Just as you do not get to decide who gets your blood when you donate at a blood drive, you cannot choose how your samples and information will be used in research.

- **Who can use the samples I donate?**

Researchers will use the samples and information you donate. The biobank will not contact you when your samples or information are sent to researchers.

- **Who decides how my samples will be used?**

A committee of experts and patient advocates will review each request for a sample to make sure the proposed research is ethical, useful, and based on good science. After the project is approved, the biobank will give researchers samples and related health information.

- **How long will my samples and information be used?**

There is no limit on how long samples and information can be stored and used. Samples can be kept and used in research until the donor asks to have them destroyed or the biobank closes. If the biobank closes, your samples may be destroyed or sent to another biobank.

- **Can I change my mind?**

If you change your mind, contact your doctor to discuss your options. The right to withdraw your samples from research varies by biobank. You should make sure you understand your options before you sign your consent form. Usually, samples and information that have already been given to researchers or used in research will not be returned. Research results from your samples or information cannot be changed or stopped. You may have the right to withdraw your samples and information that have not yet been used in any research.

- **Will I receive the results of research done on my samples?**

You will receive the results from your medical tests (such as a biopsy or blood test). But, you will not receive the results from research done on your samples.

- **Why won't I receive the results of research done on my samples?**

Donated samples are used for broad research and future discoveries, not for discovering information for each patient. Researchers may publish articles about their findings but they will not identify the individuals whose samples were used.

- **Will donating samples or information learned from my samples change how my doctor and insurance company treat me?**

Neither you nor your family will be treated differently after you donate samples. There are measures in place to protect your privacy.

- **Why do you need information from my health records?**

In order to do research with your samples, researchers may need to have some information about you. This information helps researchers learn more about the specific diseases and treatments that they are studying. Information that researchers need may include:

- Your gender
- Your racial or ethnic group
- Your age
- Your family history
- Your medical history



“I donated my samples because I wanted to help other people in my family and my community.”

- **How do I know that my privacy will be protected?**

One of the most important things for biobanks is to keep your information private. Biobanks are not allowed to release your personal information without your consent. To protect your privacy, your samples will be coded with a random number instead of your name. Your address, phone number, Social Security number, date of birth, and anything else that could identify you will be removed before the records are sent to the researcher. Federal law requires the protection of your private medical information.

- **Are there any risks?**

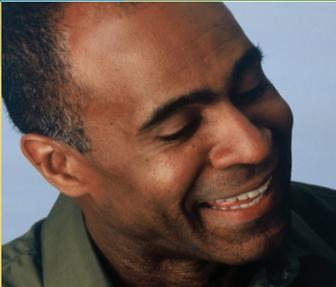
- There are very few risks to donating your samples for research. The greatest risk is the accidental release of information from your health records. The chances that your information will be released outside the biobank are very small. There are security measures designed to prevent this from happening.
- You may be uncomfortable with the fact that the biobank will not contact you before your samples are selected for research studies. If, because of your religious or other beliefs, you would not want your samples to be used for certain types of research, donation may not be right for you.
- Your doctor or nurse will prepare you for any physical side effects you may have from having a medical procedure, such as bruising or soreness at the place where your samples are taken from.



Is Donation Right for Me?

Take time to ask yourself, your family, your doctor, your nurse, and other important people in your life the following questions:

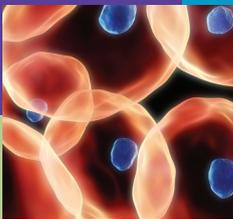
- Is donation right for me?
- Do I understand my options? Does my family?
- Do I understand any unlikely, yet possible, privacy risks to myself and my family?
- Do I understand everything on my consent form? Or are there parts of my consent form I need to discuss further?
- Am I comfortable with experts making decisions about how my samples will be used in research without contacting me?
- Do I understand that I am not going to receive research results from biobanks?
- Do I still have questions?



“I am a cancer survivor. I donated my samples during a medical procedure. It made me and my family feel good to know I could help medical research.”

For More Information ...

- Talk to your doctor or nurse
- Contact the Office of Biorepositories and Biospecimen Research
E-mail: nciobbr@mail.nih.gov
Web: <http://biospecimens.cancer.gov>



Researchers use your samples, along with samples from thousands of other patients, to look for ways to prevent, find, or treat health problems like diabetes, heart disease, and cancer.

For answers to your cancer questions, call the
NCI's Cancer Information Service at
1-800-4-CANCER (1-800-422-6237)



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NIH Publication No. 12-7933
Printed August 2012

