



What have other patients who have participated and provided tissue samples for this type of research said?

"I realized that I am part of a larger community and that I benefit from the participation of others who have donated before me. Life is more than what I am going to get out of it. I want to make a difference for other patients who come after I do. If I can help other people with the disease, I am going to do it."

"It is active altruism – not just saying you want to help others but actively doing something that could change cancer treatments for future patients."

"I felt empowered by joining the trial. It was very satisfying to help other patients."

"I was a lot less apprehensive because the tissue sampling was done as part of a clinical trial where there is careful monitoring from my health care team and ongoing education and support from my research nurse."

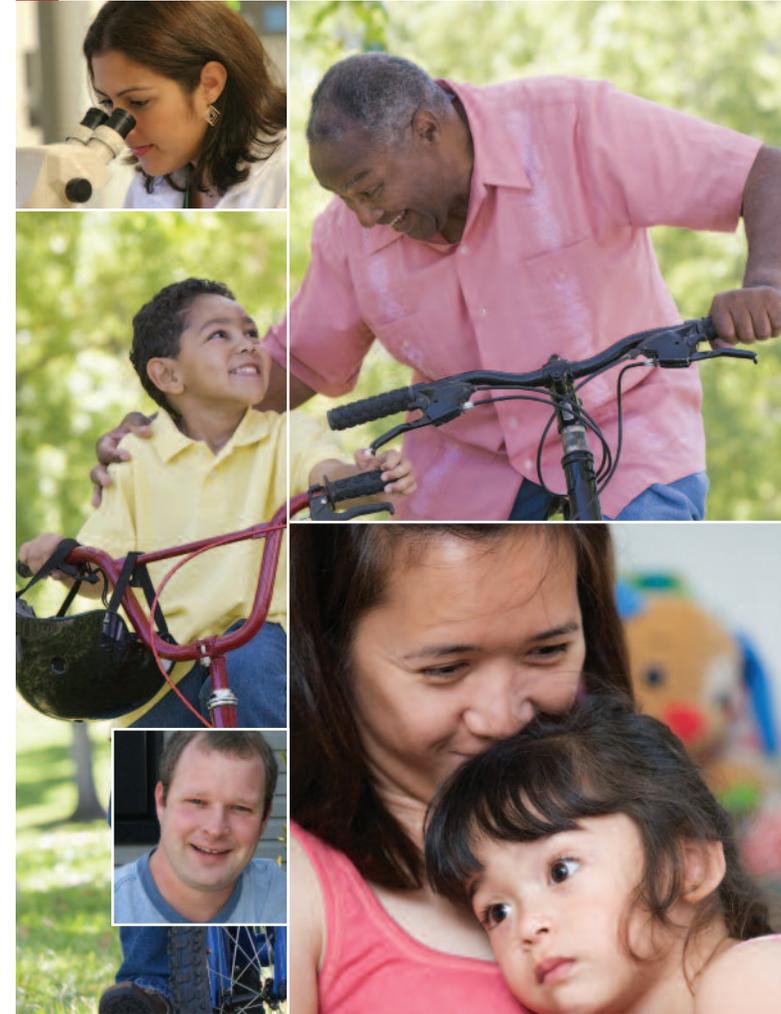
"The researchers are doing this trial so that, in the future, they can choose the right drug for the right person. The next person who is sitting where I am sitting today will get the treatment that works for him or her."

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For more information or to determine whether you are eligible to participate in a specific trial, please contact the following:

How You Can Help Advance Cancer Research

Providing Tissue Samples as Part of a Clinical Trial



Research Advocacy Network

Advancing Patient-Focused Research

Why might I want to provide tissue samples?

Your participation in a clinical trial with tissue samples could help improve the cancer treatments for future patients.

The drugs used to treat cancer today work for some patients but not for others. Patients and healthcare providers alike want improved and better-tailored cancer treatments for future generations. Doctors want to target the right treatment to the right person at the right time.

“I needed hope that the research might benefit me. I know now I am helping create tomorrow’s medicines today. Clinical trials are how we get all of our drugs approved. The treatments I am offered today came from clinical trials where other patients like me participated and donated blood and tissue samples for research.”

— Patient

Before this can happen, however, researchers need to know more about how cancer cells respond to treatment. This is where you can help. Researchers critically need tissue samples from patients like you in order for cancer research to progress. They need to examine cancer cells in tissue samples provided before treatment, during treatment, and after treatment in order to understand how the cells change in response to therapy. Researchers can best determine this by sampling the cancerous tissue from actual patients several times over the course of a clinical trial.

Healthcare providers only ask patients to volunteer to provide tissue samples when it is considered safe and appropriate. However, it is important to discuss the risks with your doctor so that you can make an informed, voluntary decision that is right for you.

What does it mean to provide samples of my tissue for clinical research in cancer?

Tissue samples may be taken from a variety of different organs, such as lung, breast, bone, skin, liver, colon, bladder, or blood. Doctors use different types of procedures depending on the type of cancer, the site from which the tissue is to be obtained, the amount of tissue to be sampled, current levels of technology, and other factors.

Researchers then study the tissue samples to determine the answers to specific questions related to the treatment. In general, the results of the research studies conducted today will primarily benefit the patients of tomorrow. In a similar way, tissue samples provided by previous patients have resulted in advances in cancer treatment options that patients see today. This includes medications that target specific subtypes of cancer and tests that help determine how likely it is that cancer will recur. For example, researchers have developed certain tests for breast cancer that help determine a patient’s risk that her breast cancer will recur and aid in her treatment decisions.

Definition:

Tissue is defined as a collection of similar cells that act together in doing a particular function in the body. When a portion of those cells is removed from the body for study, it is called a tissue sample or may be referred to as a biopsy.

What are some questions I may want to ask my doctor about providing tissue samples for research?

- What is the purpose of the research and what do you hope to learn?
- Am I likely to benefit from providing tissue samples?
- How will the tissue sampling procedure be performed?
- Will the tissue sampling procedure hurt?
- Is the tissue sampling procedure risky to me?
- How many tissue samples are you requesting of me? Will they be taken at different times? If yes, how many and how often?
- What happens if I provide one tissue sample and then decide I do not want to provide any more? Can I leave the study at any time?
- Do I have to make a special trip to the hospital or clinic to provide the tissue sample or will it be done as part of my regularly scheduled appointments?
- Will these samples be used only in this study or stored for any other purpose in the future?
- How will my privacy (and my family’s privacy) be protected?
- Will I be able to find out the results of the tests conducted on my tissue samples?
- Will my insurance cover the costs or is this included in the study?



The answers to these questions depend on the specifics of a trial and your situation and are best addressed by your healthcare team.