Universal Consent for biological samples
In support of precision health

Frequently asked questions

What is a biological sample?
A biological sample is any bodily fluid or tissue (e.g., blood, saliva, urine, skin or other tissues) that may be collected when you go to the doctor or have a medical procedure. More often, these samples are collected to help diagnose or monitor your health condition. After being used, anything that’s left over is thrown away or destroyed. With your permission, these leftover materials will be sent to the UCLA BioBank for research instead of being thrown away.

What is the UCLA Biobank?
The UCLA BioBank collects biological samples from as many people as possible. It then codes the samples and removes any information that could identify you. The BioBank then sends the samples, along with some of your health information, to approved researchers who will use the information to find new ways to prevent, detect and treat health problems.

Will my consent decision affect my care?
No. Your universal consent decision (opting in or out of donating your biological samples) will have no impact on your clinical care. For patients over the age of 18, if you say YES to the collection of an additional blood tube and/or saliva sample, the clinical staff will need to know in advance in order to collect the additional sample. No matter what you decide, it will not affect your relationship with UCLA Health or the services you are receiving.
Why do we need an extra tube of blood?
For patients over the age of 18, having an extra tube of blood (up to 2 teaspoons) or in some cases saliva provides us with enough volume for multiple research purposes and permits certain research not possible on leftover samples.

How will samples be collected?
We will collect some biological samples from some of your future routine clinical lab work done at any UCLA Health laboratory. With your permission, we may: 1) use leftover biological specimens from any future routine lab work done at any UCLA Health laboratory, 2) collect an extra tube of blood as part of a future blood draw or IV placement during a routine visit, and/or 3) collect saliva if you are at a clinic that collects samples for precision medicine.

*You will not need to undergo any additional needle sticks, tests or procedures.

How long will my samples be stored?
Your samples will be stored indefinitely.

How could my samples be used for research?
Your samples may be used for a variety of research purposes (e.g., cancer, heart disease, diabetes) and for product development.

Examples:

a. Genetic research
Your sample may be used to study how genes affect health or respond to treatment. Genes contain pieces of DNA that control how our cells and bodies develop and work. The DNA code is what you inherit from your parents and pass on to your children. Researchers can use a number of methods, including whole genome sequencing, to look at parts or all of your DNA code.
b. Scientific databases
Researchers also put genetic and other non-identifiable information about you and your health conditions, into a research database. This increases knowledge and can make future research discoveries happen more quickly.

c. Other uses
Researchers may use your samples to create new products useful for research or clinical treatment.
Your sample may include cells that can be made to grow indefinitely in the laboratory, called a "cell line," or your sample could be used to develop or test new treatments.

Who will conduct research on the samples?
Only researchers and research projects approved by a UCLA research-review process may receive samples for research. Most samples will go to UCLA researchers, but we may also choose to share samples with researchers from other universities, government researchers and researchers from private companies that work on developing new tests or treatments.

Will I get any results from research done with my samples?
You will not get any results back unless you let us know that you want to receive genetic results. The research community will not know who you are but the UCLA Biobank will be able to work with your healthcare team to notify you only if there are results that may affect your care. Please know that there is often a delay of months to years before a result is available. If you do not want to be notified of any results, UCLA will publish a newsletter that provides overall information about new discoveries made from the samples. If any results are returned to you, a genetic counselor will be available to provide more information on your results either in person or over the phone. If you or your doctor are concerned that you have a medical condition that requires genetic testing, we encourage your doctor to order a clinical genetic test in order to get you answers sooner. Please know that this does not substitute the need for a clinical genetic test.
Are there financial factors I should consider?
You will not be charged for donating your samples and you won’t receive any money for doing so. If there is commercial value, it will belong to UCLA and its collaborators. You will not be paid if any new products, tests or discoveries result from any research performed with your samples.

Who benefits from biological samples?
Your samples will be used to advance science and better understand specific diseases. In the past, some UCLA samples have developed new treatments for serious diseases. The research discoveries in the future may allow for more personalized therapies for patients — a primary goal of precision health at UCLA.

Are there any risks?
There are no physical risks. There is a very small chance that someone could obtain information that would connect the sample to you. Since only you have your unique genetic makeup, information about your ancestry, ethnic group or other people with your disease might be identified and connected with your sample. There is also a small chance that information from your health records could be accidentally released. Currently, only large state and federal agencies have the ability to identify individuals just based on a complete DNA profile. We cannot predict how future technology might affect confidentiality.

Federal and California laws provide certain protections against discrimination based on genetic information.
Some people may have moral, religious or cultural concerns about some kinds of research.

How will my privacy be protected?
UCLA will remove your name and other information that could identify you before sharing your samples for research. A list of names and matching code numbers will be kept separate from coded samples and data. Only authorized UCLA staff can access this list.
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