

Information Sheet

Blood Tests & Storage

Why do we collect blood for the Alzheimer's Disease Research Center (ADRC) study?

The long-term goal of the ADRC study is to learn about how Alzheimer's disease and related disorders are developed and what causes them, find new signs that indicate aging and dementia, and look into genetic risks.

Researchers study biomarkers, which are measurable indicators of diseases or conditions in the body. Blood is a useful biomarker to help understand aging, disease progression, and treatment response.

What we study

We run standard blood tests: lipid profile, TSH, B12, folate, hemoglobin A1C, homocysteine, C-reactive protein and COVID19 antibody assay. We will share these findings with you.

We study DNA, which is passed down from your parents and carries a code, in the form of genes. Differences in DNA can help explain why some people develop certain diseases, while other people do not.

For example, we will examine your DNA to determine which form ("genotype") of a protein in your blood, called apolipoprotein E (ApoE), you have inherited. This is of interest because people with one form (genotype) of this protein (about 15% of the population) have a much greater likelihood (risk) of developing Alzheimer's disease than people with other forms (genotypes) of this protein. The results of your ApoE blood tests are used for research and will not be made available to you. ApoE genotyping is not a test for AD and is not part of the recommended evaluation for AD.

We may also perform a whole genome analysis on your DNA sample. Usually, researchers study just a few areas of your genetic code that are linked to a disease or condition. In whole genome studies, all or most of your genes are analyzed and used by researchers to study links to the disease under study. These genetic tests will not be able to determine your risk for genetic diseases or have any benefit to you. Therefore, the results will not be shared with you.

What to expect at your study visit

Prior to your study visit, you will need to fast for 4 hours. You can only drink water and take medications during this time. We will collect 14 teaspoons of blood from a vein in your arm. After the blood draw, you will be provided with a meal of your choice.

Blood storage

The NYU Alzheimer's Disease Research Center (ADRC) is responsible for handling and analyzing data from samples.

Data is collected and stored at the National Alzheimer's Coordinating Center (NACC), which is the main hub for collaboration and communication between ADRCs across the United States (funded by the National Institute on Aging). Sharing data is a powerful tool to advance knowledge of the disease.

Analysis includes looking at DNA to conduct "whole genome studies," which means looking at the entire DNA sequence rather than just looking at one gene.

Samples are stored for current and future research purposes. Some samples are stored at the National Centralized Repository for Alzheimer's Disease and Related Dementias (NCRAD), which is supported by the National Institute on Aging.

Some samples will initially be stored at NYU ADRC (145 East 32nd Street) and then sent to SciSafe Inc. in New Jersey for storage and use in ADRC's ongoing research projects. These samples are stored until they are used up. Only the principal investigator (person in charge of research) and authorized staff will have access to your samples.

If you decide to allow us to store your samples and later change your mind, you can request the destruction of remaining samples by contacting the principal investigator in writing.

Ensuring confidentiality

Your samples will be labeled with a unique code so that you cannot be readily identified from them. The samples and data will be sent with only your unique code number attached.

Coded, deidentified samples are sent via courier. Your name or other directly identifiable information will not be given to central banks. The principal investigator will maintain a link between your unique code and identifiable information in a separate, secure location (password-protected behind NYUL firewall, and accessed only by authorized staff).

There are many safeguards in place to protect your information and samples while they are stored in repositories and used for research. Samples are deidentified and stored in secure facilities with restricted access. Electronic data are deidentified and stored on network drives protected by institutional firewall. Researchers who wish to use the data from national banks for their projects must submit a formal request and accept the terms of the data use agreement designed to protect the privacy of study participants, ensure appropriate data use, and inform the repositories of any resulting publications. Data may be accessed only by trained study personnel and cannot be distributed to third parties.

After the study is completed, the de-identified, archived data will be transmitted to and stored at NACC for use by other researchers including those outside of the study.

With your permission, we store your leftover samples for future research projects, which include but are not limited to, the investigation of biomarkers of aging and dementia as well as genetic material.