

Mayo Clinic Biobank

Privacy and Security

Thank you for your interest in the Mayo Clinic Biobank. Mayo Clinic staff understands that your health information is personal. In this pamphlet you will find details about the privacy and security measures related to the medical information you are sharing with the Biobank. Your medical information is made up of answers you gave on the questionnaire, information from your medical record, and data from your donated sample.

How are the samples and information stored?

At Mayo Clinic, the Biobank samples are secured in locked freezers, and access to them is limited. The building is under constant video surveillance. Personal medical information is stored in computers that are protected by electronic security measures.

Mayo Clinic staff cannot control how the samples and information are stored once they leave Mayo Clinic.

How will researchers get access to the Biobank samples and information?

Specimens will not be released to any researcher until the proposed research study has undergone a rigorous review and approval process by the following committees:

- 1) The Mayo Clinic Institutional Review Board (IRB) which ensures that all projects are ethical and appropriate. <http://mayoresearch.mayo.edu/mayo/research/irb/index.cfm>
- 2) The Mayo Clinic Biospecimen Subcommittee of the Mayo Clinic IRB which ensures that only the necessary amount of specimen is collected and used and that all specimens are used only for research that has been approved by the Institutional Review Board.
- 3) The Biospecimen Trust Oversight Group (BTOG) which consists of Mayo Clinic physicians and scientists as well as community members will review each request for specimens and medical information to ensure that it is both appropriate and scientifically valuable.

Who will have access to the samples and information?

Samples and information will be made available to Mayo Clinic staff only for approved research studies. Mayo Clinic also often works with centers and investigators outside of Mayo on various research projects. When you donate to the Biobank, you give Biobank staff permission to share your sample and information with these other researchers, universities, and hospitals. The same approval process will be used for all requests for samples, even those that come from outside Mayo Clinic.

Information provided to researchers will not contain any information commonly used to identify you, such as your name, address, or birth date.

Health information and samples will only be shared for the following reasons:

- for medical research
- to make sure researchers using the Biobank are following the rules
- to make sure study findings are correct

Will researchers know which sample and information is mine?

Your samples will be given a unique code that very few people will know. No one will be able to identify you just by looking at your sample. For example, Joe Smith will become sample # 5096739651.

Researchers will not be able to connect the code to your name unless they have been given special access. For example, Biobank staff may need to contact you about your sample or information in order to perform a research study. They will try to make sure that no one connects your name to your samples unless it is necessary.

Your medical information will be **de-identified** before given to a researcher. This means that your name, address, Mayo Clinic number, social security number, and anything else commonly used to identify you will be taken off your health records. So, when a researcher (at Mayo or outside) looks at your medical records, they will not be able to tell whose records they are by looking at them.

Although investigators will not have access to information commonly used to identify you, you could be identified through your samples. Your DNA is one of a kind, like your fingerprint. Just like a fingerprint, even if your DNA doesn't have your name attached, people could still use it to identify you. In order to link de-identified DNA to you, a sample of your DNA with your name on it must be available for comparison. Although it is unlikely that this will happen, it is possible. For example, if your DNA is stored somewhere with your name attached and those samples are matched with the samples you donate to Mayo Clinic, you could be identified.

Although both Mayo Clinic and its research partners take measures to protect the privacy of research samples, there will always be a chance that you could be identified through your sample.

What will happen to my samples and information when I die?

Once you die, your sample will be considered a gift to Mayo Clinic. That means Mayo Clinic can continue using it in the ways described in the consent form forever, even if your family wishes that you had not donated a sample to the Biobank.

Since your samples contain your genetic information, your family may want access to them after you die. On the consent form you can choose whether you would like to allow your next-of-kin access to your sample after you die.