

# Precure Research Study

## Frequently Asked Questions

### General Information

#### How many people are taking part in the Mayo Clinic Precure Study?

The Mayo Clinic Precure team will be enrolling up to 100,000 people in the study.

#### What does the Mayo Clinic Precure test for?

The study tests biospecimens, such as blood, urine, saliva, and stool, to better understand why a disease or disorder occurs and how it progresses over time. This knowledge could aid research and impact future patient care.

#### Who is funding the Mayo Clinic Precure Study?

The study is funded by Mayo Clinic and Regeneron Pharmaceuticals, Inc. Regeneron will pay Mayo Clinic to cover costs related to running the study.

#### Who should I contact if I didn't get my sample collection kit?

The study team will send you more information by email. The team will send your sample collection kit after you sign the consent form and verify your mailing address. If you don't get your sample collection kit within two weeks of the email stating it was sent to you, please contact the study team at [MayoClinicPrecure@mayo.edu](mailto:MayoClinicPrecure@mayo.edu).

### Results from the Mayo Clinic Precure Study

#### Will I get test results from this study?

Tests are done for research purposes - not to help with your healthcare. That is why in most cases you won't get the test results.

But if a finding might affect your health or your family's health, the study team will contact you. You can choose whether to be given this information. If you decide to follow up on the information you receive and more medical testing or care is needed, you or your insurance will be responsible for those costs.

## Will my Mayo Clinic electronic health record include test results from the Mayo Clinic Precure Study?

No. The study team won't enter the test results into your Mayo Clinic electronic health record.

## Can I get study test results by going to Patient Online Services, Mayo Clinic's patient portal?

No. The study team won't enter test results into Patient Online Services.

## What happens if future research using my genetic information finds new results that affect my health?

If future research finds new results that could affect your health, the Mayo Clinic Precure team or another research team will contact you. Please read the Data Privacy, Insurance and Discrimination section below for more information about who might use your genetic information and how it's protected.

## Can I stop taking part in the Mayo Clinic Precure Study?

Yes. You can choose to leave the study at any time. Please contact the study team at [MayoClinicPrecure@mayo.edu](mailto:MayoClinicPrecure@mayo.edu) if you want to stop taking part.

## Data privacy, insurance, and discrimination

### Who will have access to my genetic data as part of this study?

Mayo Clinic researchers will have access to your information, including your genetic data and samples.

Researchers or others outside of Mayo Clinic, including other academic or medical institutions or companies may request your information samples for future research/as part of other studies. Read more about this process in [Who can use the Mayo Clinic Precure Registry?](#)

### Are there laws that protect the privacy of people who take part in the research?

Yes. Mayo Clinic strictly adheres to federal laws that protect the privacy of people who take part in research studies. An institutional review board oversees the Mayo Clinic Precure Study and makes sure the study follows all laws.

## Will Mayo Clinic use my genetic information for other research?

Yes. Information from the Mayo Clinic Precure Study will help researchers at Mayo Clinic and other institutions now and in the future. By taking part in this study, you are helping researchers and others study the roots of diseases and disorders and find new treatments.

## Can I request that Mayo Clinic or other institutions not use my genetic information?

Yes. You can email the study team at [MayoClinicPrecure@mayo.edu](mailto:MayoClinicPrecure@mayo.edu) to request that the study stop using your information. If your information has already been shared with researchers or others, the team can't guarantee that all data will be deleted.

## Will the public see my genetic information?

No. Neither Mayo Clinic nor other institutions will make your genetic information public.

It is helpful for researchers to share data they get from studying samples and information. They do this by putting de-identified data into scientific databases (like ClinVar, which is managed by the National Institutes of Health). Researchers can study the shared data to learn even more about health and disease.

If you agree to take part in the Mayo Clinic Precure Study, researchers may place some of your genetic and health information into one or more scientific databases. Researchers will never place your name and other information that could readily identify you in a scientific database.

## Mayo Clinic Precure Registry

### What is a registry?

A registry is a library of patients' samples and information (i.e., biological, medical etc). It also can include biological samples such as blood, urine, saliva, and stool.

The Mayo Clinic Precure Registry contains genetic information and biological samples from all people who take part. This registry will support researchers and others for many years. By storing the genetic information and biospecimens of many people in one registry, researchers save time because they do not need to recruit people to take part in each new study.

## What are the benefits of having my genetic information and biospecimens in a registry?

By including your genetic information and biospecimens in a registry, you are helping to support future research.

## Who can use the Mayo Clinic Precure Registry?

Mayo Clinic researchers, outside researchers, industry professionals and private companies may ask to use information and biospecimens from the registry for new studies or commercial projects. Mayo Clinic has strict policies in place to keep your information private and outlines who can use the registry and how.

### Access for Mayo Clinic researchers

Mayo Clinic researchers who aren't involved with the Mayo Clinic Precure Study may ask to use the registry for future research. If you join the Mayo Clinic Precure Study, these Mayo Clinic researchers may get information that can identify you along with the information collected about you in the study.

### Access for others outside Mayo Clinic

People from outside Mayo Clinic may ask to use information or samples from the Mayo Clinic Precure Study. These people may be from for-profit companies or they may be doing research to make money.

Anyone who wants to use the Mayo Clinic Precure Registry must first contact Mayo Clinic for permission. Mayo Clinic may send information or samples collected as part of the study to researchers who request them. However, no personal information that can readily identify you will be given to them. A code will be assigned to any data or samples that are shared. Only the Mayo Clinic Precure team at Mayo Clinic can link the code to you.

## Could Mayo Clinic or others use data in the registry to make money?

Yes. Some examples of how the study's registry could be used to make money include:

Charging a fee to researchers or private companies. This fee would cover the costs of sharing the data in the registry, such as sending digital genetic information securely.

Creating agreements with outside groups or institutions. The outside groups may pay to use genetic information from the registry.

Using information from the registry to discover new medicines, medical tests or other medical advances. Mayo Clinic or other groups may make money from these discoveries.

## What happens to my samples and information when I die?

When you die, your genetic information and biological samples will be considered a gift to Mayo Clinic. That means Mayo Clinic can continue using them forever in the ways described in the consent form.

## Can I withdraw my information and biospecimens from the Mayo Clinic Precure?

Yes. You can remove your information or biological samples from the Mayo Clinic Precure's registry at any time. If your genetic information or biological samples have already been shared with researchers, your information may not be removed from those studies. However, your data or biological samples will not be used for future research.

You can request that the study stop using your data or biological samples by emailing the study team at [MayoClinicPrecure@mayo.edu](mailto:MayoClinicPrecure@mayo.edu) .