

Key information about the study

As part of our ongoing study of the health and financial situation of people residing in the U.S., our next research project is to analyze data from outside sources along with the answers that you and the other members of the Understanding America Study provide in our surveys. That that will allow us to better understand how individual health, access to healthcare, and finances affect our lives.

This is a short summary of the key information about this study. More detailed information is listed later on.

Key Information

- Being in this research study is voluntary – it is your choice to participate or not.
- You are being invited to take part in this study because you are a member of the Understanding America Study who is age 65 or older. The purpose of this study is to use health data collected by Medicare and Medicaid to help understand the needs of older U.S. residents.
- There is a small risk that people who are not connected with this study will learn your identity or your personal information.
- There are no direct benefits to you from taking part in this study. However, your participation in this study may help us learn how health, access to healthcare, and finances affect Americans' lives. It may also help us understand how better to inform Americans about the choices that are available to them.
- As with all of our special projects, your decision does not affect your participation in the UAS. If you decide not to participate in this research, you can continue to participate in the Understanding America Study, doing surveys.

What is the purpose of the this study?

One of the goals of the UAS in general, and the purpose of this study, is to understand the health and financial situation for older Americans. We do this through conducting UAS surveys, and also by obtaining other information that can provide insights.. The purpose of asking you for permission to combine your survey data with data from Medicare and/or Medicaid is to reduce the burden on you as a survey respondent, and to help us ensure that we are working with accurate data. About 5000 UAS participants may take part in the study. This research is being funded by the National Institute of Aging, and the Social Security Administration.

Researchers study this information to create findings that may include

- New knowledge about the relationships between access to health care and health
- Understanding of how changes in a financial situation (e.g. retirement) may impact access to care.

People volunteer to join the study for different reasons including:

- To help policy makers understand how people in the country are doing in regards to health, finances, and access to care
- To make sure research findings benefit all types of people – regardless of age, race, ethnicity, or geography

We believe that giving members the chance to volunteer for research studies like this one is one of the benefits of being a member of the Understanding America Study.

What information do you share?

If you join, you will agree to allow us to use your Medicare and/or Medicaid number to combine the following information. (If you do not know your Medicare or Medicaid number, we can use your name, address, sex and date of birth and/or the last four digits of your social security number.)

- Your Information from various surveys that you have taken in the UAS or will take in the future
- Your Information from Medicare and/or Medicaid use records.

Your information will be de-identified. This means information like your name and address, and your Medicare and/or Medicaid number will be removed and replaced with a unique number.

If you agree to participate, you will provide your Medicare / Medicaid member numbers, and we will use them to find your records so that they may be linked to survey data.

How will the data from this study be used in the future?

De-identified data from Medicare and/or Medicaid, collected as part of this research and combined with your survey data, will be kept in what is known as a “secure data enclave”. A data enclave is a computer that can only be accessed by researchers and policy analysts who obtain permission, and who are only allowed to use the data for specific purposes. In these secure conditions, your data will be used in this study. and in future research studies, by researchers and analysts associated with the UAS as well as others.

Information that identifies you (such as your name or any identifying numbers) will never be included in the information that is shared for research or analysis now or in the future.

If you do not wish for your data to be stored in the secure data enclave for future research and analysis, you should not participate in this study.

How is my health information kept private and secure?

Joining is safe, secure, and private

The health information we obtain from Medicare/Medicaid will be de-identified. This means that your name and other personal information are removed. It is then replaced with a unique study number.

Only researchers and analysts who do studies that are approved by research ethics review boards have access to the data.

Your information is protected

The UAS is serious about protecting your privacy and information.

The data will be stored in what is called a “secure data enclave”. This means that the server can only be accessed by people who have signed agreements to never try to identify the people in the study, and have obtained a approval of their proposed research from a research ethics board . Everything they do with the data is checked and monitored, to protect your privacy.

Will the study share your personal results with you?

You should not expect to get personal results from taking part in this study. We do not expect that results will be the kind of information that you would use to make decisions about your life.

UAS will not give identifiable results about you to anyone else. Eventually, researchers may be able to use the findings made from your participation to change policy and help people who struggle with access to health care.

Are there any risks?

There are no physical risks to you. The biggest risk is that someone could get access to the data the UAS has stored about you, despite best efforts to keep the information safe. The UAS believes the chance that this will happen is very small, but there is no guarantee that there is no risk. We will make every reasonable effort to protect your privacy.

What are the benefits?

There are no direct benefits to you. Society may benefit from this research if policy changes are made that benefit others.

Research Projects and Findings Should Represent Everyone

When all types of people are part of research, the findings benefit everyone. People are different, so if only certain groups participate in research, only certain groups may benefit from the findings.

UAS welcomes all UAS members who are 65 or older and have Medicare or Medicaid to join. We welcome people who are:

- healthy or sick,
- from all different socioeconomic levels,
- from different areas of the country, and
- from all races and ethnicities.

The more people who join in, the more powerful the findings will be.

Why are you asking me to participate?

The UAS is asking all members of the UAS who are 65 years of age or older, to participate.

It takes thousands of records to be able to draw accurate conclusions from our research. Researchers need to collect and study information of many people from the entire population. This includes healthy people and those who are not, people from all walks of life across the country. All groups can help researchers understand disease and improve health care.

Am I required to participate in order to keep doing surveys?

No. Joining is your choice. If you decide not to join now, or to withdraw your consent later, your decision will not affect your participation in the Understanding America Study.

How can I participate if I choose to?

If you agreed to participate in the UAS survey where we described the study and asked if you would like to join it, you can contact the UAS helpdesk by phone (855) 872-8673 or by email (uashelp@usc.edu), and request to be added to the study.

What if I decide I no longer want to participate?

This is a volunteer study. You can leave the study at any time. If you choose to leave the study you can contact the UAS helpdesk by phone (855) 872-8673 or by email (uashelp@usc.edu), and request to be withdrawn from this study.

Refusal to participate or stopping your participation will involve no penalty. If you stop being in the research, already collected data may not be removed from the study database.

You will be asked whether the investigator can continue to collect data from your records. If you agree, this data will be handled the same as the research data. No new information will be collected about you by the study team without your permission.

How will you protect me as a study participant?

We believe that research is the key to understanding the financial and health needs of Americans and also that your privacy must be safeguarded. When you participate in research, it is very important to us that we protect your information. We want to share some ways that we keep study participants safe.

Some people worry about participating in research. Often, it is because of bad things that have happened in the past. In the past, some research was not ethical (not the right thing to do). Before rules and regulations were created and required for all researchers to understand and follow, some people hid the truth about research.

However, now we Have Research Safeguards...

A USC Institutional Review Board (IRB) is a research ethics board that reviews all research studies before they start. Members of the IRB include researchers, experts, and community members. The IRBs include people who bring many different views to the review of research.

The IRB makes sure that:

1. The rights, safety, privacy, and dignity of all participants (human research subjects) are protected.
2. The benefits of the research outweigh the risks.
3. The risks to people who participate are as low as possible.
4. All research activities are reviewed so that all regulations are followed.
5. All research activities are reviewed so that all ethical principles are met.

UAS goes to great lengths to reduce risks of harm for all its participants.

We also have a Certificate of Confidentiality

The UAS has a Certificate of Confidentiality from the federal government (through the National Institutes of Health).

Having the certificate means: No one can force the UAS to share information that may link to you. This includes a court subpoena by federal, state, or local civil, criminal, administrative, legislative, or other proceedings. However, we will share data about you with the IRB if they need to review our research records to make sure the research is being done right.

All Staff undergo extensive training on Human Subjects Research and Informed Consent

All UAS research staff must complete special training called Human Subjects Training. 'Human Subject' is another word for 'participant.' In this training, research staff learns about ethical research and how to protect participant rights.

Learning about ‘informed consent’ is an important part of staff training. Before a person participates, you should understand what you are being asked to do, and why. Knowing this can help you make an informed choice about if you want to participate. This process is called ‘informed consent.’ Informed consent is required for most types of research.

To obtain ‘informed consent’ these things must happen:

Researchers must tell participants what they will be asked to do if they sign up for research.

A person must be told the benefits and risks of being a part of the research project.

A person must be told they will not personally benefit from the research.

A person must be told how they can withdraw from (leave) the project, if they change their mind.

This information is found in the survey that you are taking, and in this FAQ. If there is anything you don’t understand about what your participation in this research entails, just ask!

Have more questions?

Contact the UAS helpdesk by phone (855) 872-8673 or by email uashelp@usc.edu and say that you would like to know more about this project.

Thank you for being a UAS participant! Whether or not you decide to participate in other projects like this one, your input into our UAS surveys is extremely important to us.