

eSMARTER Study FAQs

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Study Overview

What is the eSMARTER study?

The eSMARTER study compares how people learn about their risk for Alzheimer's disease. People are randomly put in one of two groups. Members of one group have a live virtual one-on-one meeting with a genetic counselor. Those in the other group will guide themselves through test results using an interactive website or online chat. The study tests if people using the website or chat respond the same way as those learning from a genetic counselor.

What does eSMARTER stand for and what does it mean?

- **E**valuation of
- **S**elf
- **M**ediated
- **A**lternative for
- **R**isk
- **T**esting
- **E**ducation and
- **R**eturn of Results

A "self-mediated alternative" means people guide themselves through their test results using an interactive website or online chat. "Risk testing education and return of results" means learning information about your risk for Alzheimer's disease based on a test, in this case a test for APOE gene type. There also is an option to learn more about your Alzheimer's risk from the results of a blood test.

What is the purpose of this study?

Participants will learn about their risk for Alzheimer's disease based on their apolipoprotein E (APOE) gene type.

One group will have a live virtual meeting with a genetic counselor. The other group will guide themselves through test results using an interactive website or online chat.

Study leaders will compare the two groups. They will learn if people getting results from a website or chat respond the same way as those learning from the genetic counselor. This will be useful as these tests become more common and more people will need their results.

Participants can choose to learn more about their Alzheimer's risk from the results of a blood test. They also will get these results from either a virtual meeting with a counselor or through a website or chat. This gives study leaders another chance to compare the two experiences.

What is APOE?

APOE is one of the many genes in a person's DNA. Genes have instructions that control how the body works. For example, genes are what give you your eye or hair color. Some genes can affect your chances of getting certain diseases. The APOE gene can affect a person's risk for Alzheimer's disease.

What do the different APOE gene types mean?

There are three types of APOE: e2, e3 and e4. Everyone has two copies of APOE. You get one from each parent, so there are six different combinations. They are e2/e2, e2/e3, e3/e3, e2/e4, e3/e4, or e4/e4.

Having one or two copies of e4 is linked to a higher risk of Alzheimer's.



It's important to know that the e4 type is just a risk factor. Having a copy of the e4 type doesn't mean you will get Alzheimer's. You may not have any copies of the e4 gene and still get Alzheimer's.

Why is it important to know APOE results?

Your APOE type tells you about your risk of developing Alzheimer's. It can also help guide decisions about treatments. For many new Alzheimer's treatments, it is recommended that you know your APOE type.

Remember, there are things besides APOE that affect your risk for Alzheimer's. These include age, education, family history and heart health.

What does the blood test measure?

The blood test measures the levels of a certain protein in the blood, called a biomarker. The biomarker is linked to your risk for Alzheimer's disease.

How can this study help Alzheimer's researchers and doctors?

The goal is to create a safe, helpful way to give results for APOE and other tests, along with education and context about Alzheimer's risk, that can be used on a large scale. This will be needed as more and more people take these tests. For many new Alzheimer's treatments, it is recommended you know your APOE results. Some people will just want to know more about their risk. So there needs to be a way to give more results to more people. And results may go straight to patients before their doctor is able to speak with them.

If the study shows people learning the results from the website or chat respond the same way as those learning from the genetic counselor, it could help solve that challenge. In the future, people could first get results from a website like the one in this study. Then they could schedule

time to speak with their doctor if needed. This could free up doctors to spend more time on patient care. It could give patients more time to prepare questions for their doctor.

Who is conducting the study?

eSMARTER is a program of the Alzheimer's Prevention Initiative. The study is led by experts from Banner Alzheimer's Institute, University of Pennsylvania, University of Michigan and University of California-Irvine.

Study Participation

Who is invited to participate?

We are inviting people who have signed up for our GeneMatch program. Those people showed interest in Alzheimer's disease and research and provided a DNA sample.

What are the criteria for participation in this study?

You must be 60-80 years old and be able to consent to join. You must also be willing to learn your APOE test results. You need internet access for getting the results and taking surveys.

You may not be able to be part of the study if you already know your APOE gene type or have problems seeing, hearing or speaking.

If I meet those criteria, is there still a chance I may be turned away from continuing with the study?

Yes. We need to make sure we have the right mix of gene types, so not everyone will be able to participate.

How will I know if I'm able to proceed in the study?

A study coordinator will contact you about next steps. If you're not able to proceed, we will let you know.



What's in it for me if I participate?

You will learn your APOE gene type and how that relates to your risk for Alzheimer's disease. You may also learn more about your Alzheimer's risk from the results of a blood test.

Will I get paid or reimbursed?

Yes. Participants will get paid for their time.

What is asked of me if I participate?

You will be asked to take some surveys before learning your APOE results. You will then be randomly assigned to get your results one of two ways. One is a virtual meeting with a genetic counselor. Or you will guide yourself through the results using an interactive website or online chat. You will also read through educational material sent by study leaders.

You'll be asked to take several more surveys about the experience of receiving your results. You can take the surveys and get your test results at home or wherever you have internet access.

You will also be asked to give a blood sample. You then have the option to learn more about your Alzheimer's risk from the results of a blood test. You will learn these test results the same way you learned your APOE results. There will be additional surveys after you learn these results.

What are the risks of participating?

There are potential risks of getting test results and giving a blood sample.

People react to getting the test results in different ways. Some may have negative emotional reactions, such as feeling sad, uncertain or anxious. The results could affect how you plan for the future or affect your family members. Not all people react this way. Some feel empowered or relieved after learning the results.

Also, learning the results could affect your ability to get certain types of insurance. There are laws in place to protect you, but they don't cover all situations. (See more below.)

For the blood sample, there is a risk of bleeding or bruising.

Study leaders always try to keep risk as low as possible. These risks will be explained to you before you agree to join the study.

How long is the study?

Your participation in the study will last approximately 6-9 months.

What happens when the study ends?

The study ends with the final follow-up survey. We may reach out to you later with updates from the study or opportunities for other studies.

Study Tests

Do I need a new test to learn my APOE type?

All participants in the study are already part of GeneMatch. That means you provided a DNA sample (a cheek swab) when signing up. We use that sample to learn your APOE gene type.

However, you will be asked to give a blood sample, even if you choose not to receive the blood test results.

How far may I have to travel for the blood work?

No travel is needed. A professional will come to your home (or a location of your choosing) to take the blood sample.



How do I schedule my blood work? Will someone contact me or set it up for me?

Someone from the study team will help schedule your blood draw.

How long will it take?

The blood draw takes minutes.

Is it free or will I be reimbursed?

There is no cost for any blood work.

Does it hurt? Is it safe?

The blood work is routine and safe. It requires a needle to take a sample of blood. There is a risk of bleeding or bruising.

Do I have to take any medications for this study?

No drugs are part of this study. eSMARTER looks at the various test results and Alzheimer's risk information. It studies the ways people learn their test results.

Test Results

Will I learn my APOE results as part of the study?

Yes. That is one of the key parts of the study and benefits of joining. You will learn your APOE gene type, which will tell you about your risk for Alzheimer's disease.

How long will it take to get the results?

We already have your information from GeneMatch. So, it won't take long for you to get the result. Timing will depend on things like the group to which you are assigned. If you are in the group that meets with a genetic counselor, it will depend on scheduling the meeting.

Will I learn my blood test results as part of the study?

Only if you choose to. This is not required. The blood work will happen between six weeks and six months after you receive your APOE results. If you are willing and able to receive your biomarker blood test results, you will be contacted when the results are ready.

How do the results affect insurance?

There is a law called the Genetic Information Non-Discrimination Act (GINA). It says health insurance companies can't treat you differently because of genetics.

This is only for health insurance. It does not cover life insurance, disability or long-term care. It's only for genetic information (like APOE), not other kinds of tests, such as a blood biomarker test.

The law also says employers can't treat you differently because of genetics. It does not apply to companies with less than 15 people.

We will not share test results from this study. Talk to your doctor before sharing the results with him or her. If you share results, they may become part of your medical record.

People may be thinking about applying for new insurance or changing what they have. It's a good idea to do this before learning the test results.

Should I tell anyone my results?

It's up to you whether to share your results and with whom. It depends on things like your relationship with a person. Or how the news might affect them or how they would react. With genetic tests, there is an effect on family members to consider. They could learn something about their own results or risk based on yours.



If you tell your doctor, it could become part of your medical record. Discuss this with your doctor before sharing results.

Do I need to check with my primary care provider before participating?

You can check with your primary care provider if you would like, but it's not necessary.

How do you decide if I get my results from the website or a person?

People in the study will be randomly placed into two groups. This is by chance, like a coin flip. The study team does not choose your group. You do not get to choose your group. Members of one group will have a live virtual one-on-one meeting with a genetic counselor. Those in the other group will guide themselves through the results using an interactive website or online chat.

What happens if I don't understand the information on the website?

If you have questions, you can always ask to schedule a time to speak to a genetic counselor. Study leaders will connect you for a virtual meeting.

If I use the website or chat, where does the information come from?

The content on the website or in the chat was made by a team of experts from Banner Alzheimer's Institute, University of Pennsylvania, University of Michigan and University of California-Irvine. It builds off years of prior research into making platforms to give these types of test results to participants.

If I get the results from a person, how will that occur?

You'll have a live, virtual meeting with a genetic counselor, such as a Zoom meeting. The study coordinator will work with you to find a time that works. Sessions will be held Monday through Friday.

Study Surveys

What is involved in the follow-up surveys? What kinds of questions will you ask?

We'll give you online surveys to complete on your own. They will ask about your feelings and emotions. We'll ask what you learned and if you liked how the results were shared. These happen up front and a few times after getting your results.

If I don't know the answers, is that a bad thing?

We want you to answer honestly. If there are things you did not learn or can't remember, we want to know that. It helps us learn about the ways we give the information. How well did they work? Do we need to make any changes?

Why are there several follow-up surveys?

This is based on other studies where people learned this type of health information. The timing and follow-ups allow us to see if things change over time.

How and where are the surveys conducted?

You can take the surveys online at home or anywhere you get internet access. You'll get an email or text when they are ready. You can complete them at a time that works for you.