



Caregiver Health-eBrain Study

Frequently Asked Questions

1. What is the purpose of the Caregiver Health-eBrain Study?

The purpose of the Caregiver Health-eBrain Study is to characterize the brain health profile as measured by Lumosity's cognitive assessment, Brain Performance Test (BPT), in caregivers of patients with Alzheimer's or other dementias, compared with aggregate scores of the general population.

2. How many people will be enrolled?

This study is open to the first 10,000 caregivers to register via the websites of the 21st Century BrainTrust® partners or directly through <http://www.health-ebrainstudy.org>.

3. Who can be part of this study?

This study is open to all caregivers taking care of patients with Alzheimer's or other dementias as well as those caregivers who have lost their loved one in the last 12-14 months.

- Care is defined as unpaid care of at least 17 hours/week to an adult 50 years or older to help them take care of themselves. Unpaid care may include help with personal needs or household chores. It might be managing a person's finances, arranging for outside services, or visiting regularly to see how they are doing.
- The age of any person providing care can be from 18-85 years of age.
- Must speak and read English.
- Must not be colorblind.

4. Do I need to live with the person with Alzheimer's or other dementias?

No, the person receiving care need not live with you.

5. What will happen if I take part in this research study?

- Informed Consent Form

First, you will be asked to sign an *informed consent form*.

- Survey

If you agree to participate in the Health-eBrain Study, you will be asked to complete a demographics survey that will ask about such things as your age, gender, education and role in caregiving. This survey will take less than 10 minutes.

- Lumosity Brain Performance Test

This test will take approximately 30 minutes or less.

- Opt-In for Future Study Communications

You may choose to opt-in to receive notices of future studies where you might be eligible to participate in. If you choose to opt-in, we will contact you via email.

6. How long will it take to be in the study?

This study includes a one-time, online self-assessment plus a survey that will take approximately 40 minutes or less to complete.

7. Can I stop being in the study?

Yes, you can decide to stop at any time. We won't delete the information from you that we have collected, but we will stop collecting any new information and will stop contacting you.

To stop participating in the study, please send an email to studycoordinator@health-ebrainstudy.org.

8. Are there side effects or risks from being in the study?

All information will be de-identified and we will do our best to protect your study information, but there may be a very small risk of loss of privacy.

9. Are there benefits to taking part in the study?

You will not obtain any direct health or monetary benefits from participating in the study, but the information you provide will be beneficial to gather information on caregiver brain health.

10. Will I get results about my brain health from the study?

No, we will not be providing any information directly to the participants on their scores.

11. How is my information protected?

We will do our best to make sure that the personal information we collect about you is kept private and secure. The Health-eBrain Study will never sell, rent, or lease your contact information. If information from this study is published or presented at scientific meetings, your name and other personal information will not be used. However, we cannot guarantee total privacy - your personal information may be given out of requirement by law (e.g., to prevent possible injury to yourself or others).

Your information will be transmitted and stored using very secure systems. The network servers where your data are stored sit behind firewalls that do not allow unauthorized access and are physically located in a secure server room that can only be accessed by critical staff members.

12. What are the costs for taking part in this study?

You will not be charged for any of the study tests.

13. Will I be paid for taking part in the study?

You will not be paid for taking part in this study.

14. Who can answer my questions about the study?

You can talk with the study researcher or study staff about any questions, concerns, or complaints you have about this study by calling 301-495-0770 and leaving a message or by sending an email to: studycoordinator@health-ebrainstudy.org.