

Brain Health Registry

Copy of Questionnaires
for Study Partners

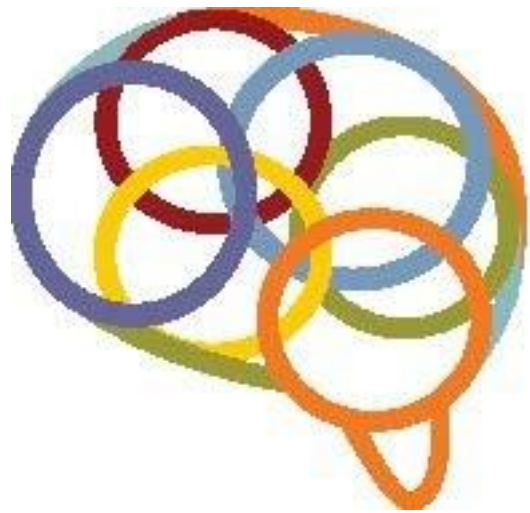


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Profile Questionnaire

Task Introduction: Thank you for participating in the Brain Health Registry. To begin, please answer some basic profile questions. Let's get started!

1) Month/Year of Birth

- 2) Gender
- Male
 - Female

- 3) Handedness
- Right
 - Left
 - Ambidextrous

- 4) What is the highest level of education you have completed?
- Grammar School
 - High School / GED
 - Some College
 - 2-year College Degree
 - 4-year College Degree
 - Masters Degree
 - Doctoral Degree
 - Professional Degree (JD, MD)

- 5) Ethnicity
- Latino
 - Not Latino
 - Decline to State

- 6) Race (Select all that apply)
- African American
 - Asian
 - Caucasian
 - Native American
 - Pacific Islander
 - Other
 - Declined to State

- 7) Location
- Knowing where our Brain Health Registry participants live is important. It helps us determine if there are additional study opportunities available in your area. If you prefer to not give your address, that's okay. We ask that you please share your postal code.

Research studies are an important step in the development of cures and diagnostic tools for all types of human diseases and health disorders.

Our goal with the Brain Health Registry is ultimately to build a large pre-screened pool of potential participants for research studies—a step that can hasten the search for cures to brain disorders. As we identify interesting research studies, we want to approach individuals who may qualify.

The final choice about participating would always be yours. We'd like to add you to the list of potential participants.

- 8) Would you be interested in participating in future studies of brain function and/or possibly clinical trials?
- Yes
 - No
- 9) We send email newsletters to our members with updates on the Brain Health Registry. We send these NO MORE THAN once a month.
- I DO NOT want to receive the Brain Health Registry Newsletter.

Introduction to CASPP questionnaire

In the menu, you can see various study tasks that we'd like you to complete, along with an estimate of how long each study task typically takes. ***Be sure to complete a study task before logging off to make sure your information is saved.***

If you don't have time to do everything today, that's okay! Do what you can and come back when you have more time. We'll also keep track of your tasks and send you periodic reminders to complete tasks.

In 3-6 months, we'll ask you to return to complete follow up tasks. This will allow us to learn about changes in your study partner's brain health over time.

Relationship

Task Introduction: It is important for us to understand how well you know the participant.

- 1) What is your relationship to _____ [PARTICIPANT'S FIRST NAME]?
 - Spouse
 - Sibling
 - Parent
 - Son or Daughter
 - Son or Daughter In-Law
 - Grandparent
 - Grandchild
 - Other Relative
 - Friend
 - Roommate
 - Paid Caregiver

- 2) How long have you known _____ [PARTICIPANT'S FIRST NAME]?

- 3) Do you and _____ [PARTICIPANT'S FIRST NAME] currently live together?
 - Yes
 - No

- 4) How many hours a week do you spend with _____ [PARTICIPANT'S FIRST NAME]?

Initial Questionnaire (Displayed to Participants as “My Study Partner and Me”)

Task Introduction: In this questionnaire, we ask a few questions about your study partner and a few questions about you. Please remember, the information you give is completely private and confidential. Also, please note that it is especially important that you complete this questionnaire privately and not in consultation with your study partner in order for your answers to be valid.

When you've finished these questions—and it should take just a few minutes to do so—you will have options for your next steps. You will be able to choose from questionnaires focusing on specific topics about you and your study partner.

Questionnaires Instructions:

First, we'd like to ask you a few questions about **YOUR STUDY PARTNER'S** brain health.

1) Are you concerned that **YOUR STUDY PARTNER** has a memory problem?

- Yes
- No
- I don't know

2) Has there been a change in **YOUR STUDY PARTNER'S** memory in the past 10 years?

- Yes
- No
- I don't know

3) Does **YOUR STUDY PARTNER** have trouble remembering whether he/she told someone something?

- Yes
- No
- I don't know

Please answer the following questions about **YOUR STUDY PARTNER**, thinking about his or her ability to perform certain tasks as compared to one year ago. In other words, try to remember how he/she was doing one year ago and indicate any change you have seen.

4) Do you feel **YOUR STUDY PARTNER** has had a significant decline in memory compared to one year ago?

- Yes
- Maybe
- No

5) Compared to one year ago, does **YOUR STUDY PARTNER** tend to ask the same question over and over?

- Yes
- Maybe
- No

6) Compared to one year ago, has **YOUR STUDY PARTNER** been misplacing things more often?

- Yes
- Maybe
- No

7) **Compared to one year ago**, does it seem to you that lately **YOUR STUDY PARTNER** is relying more on written reminders (e.g., shopping lists, calendars)?

- Yes
- Maybe
- No

8) **Compared to one year ago**, does **YOUR STUDY PARTNER** need more help from others to remember appointments, family occasions or holidays?

- Yes
- Maybe
- No

9) **Compared to one year ago**, does **YOUR STUDY PARTNER** have trouble recalling names, finding the right word, or completing sentences?

- Yes
- Maybe
- No

10) **Compared to one year ago**, is **YOUR STUDY PARTNER** having more trouble driving? (e.g., does he/she drive more slowly, have more trouble at night, tend to get lost, have accidents?)

- Yes
- Maybe
- No

11) **Compared to one year ago**, is **YOUR STUDY PARTNER** having more difficulty managing money (e.g., paying bills, calculating change, completing tax forms)?

- Yes
- Maybe
- No

12) **Compared to one year ago**, is **YOUR STUDY PARTNER** less interested in social activities?

- Yes
- Maybe
- No

13) Do you believe, based on your own observations or comments from **YOUR STUDY PARTNER'S** co-workers, that **YOUR STUDY PARTNER'S** work performance (paid or volunteer) had declined significantly, **compared to one year ago**?

- Yes
- Maybe
- No

14) Does **YOUR STUDY PARTNER** have more trouble following the news, or the plots of books, movies or TV shows, **compared to one year ago**?

- Yes
- Maybe
- No

15) Are there any activities (e.g., hobbies, such as card games, crafts) that are substantially more difficult **YOUR STUDY PARTNER** now compared to one year ago?

- Yes
- Maybe
- No

16) Compared to one year ago, is **YOUR STUDY PARTNER** more likely to become disoriented, or get lost, for example when traveling to another city?

- Yes
- Maybe
- No

17) Compared to one year ago, does **YOUR STUDY PARTNER** have more difficulty using household appliances (such as the washing machine, VCR or computer)?

- Yes
- Maybe
- No

18) Has **YOUR STUDY PARTNER** ever been diagnosed with Mild Cognitive Impairment (MCI)?

- Yes
- No
- I don't know

19) Has **YOUR STUDY PARTNER** ever been diagnosed with Alzheimer's disease?

- Yes
- No
- I don't know

The next set of questions are all about YOU and YOUR health.

20) Are you concerned that YOU have a memory problem?

- Yes
- No

21) Do YOU have trouble remembering if YOU have already told someone something?

- Yes
- No

22) Compared to 10 years ago, would you say that there has been a change in YOUR memory?

- Yes
- No

23) In general, would you say YOUR health is:

- Excellent
- Very Good
- Good
- Fair
- Poor

24) Compared to one year ago, how would you rate YOUR health in general now?

- Much Better
- Better
- Same
- Worse
- Much Worse

25) Over the last two months, how often have YOU been bothered by having little interest or pleasure in doing things?

- Not at all
- Several Days
- More than half the days
- Nearly every day

26) Over the last two months, how often have YOU been bothered by feeling down, depressed, or hopeless?

- Not at all
- Several Days
- More than half the days
- Nearly every day

27) Stress means a situation in which a person feels tense, restless, nervous or anxious or is unable to sleep at night because his/her mind is troubled all the time. During the past 12 months, would you say YOU experienced:

- A lot of stress
- A moderate amount of stress
- Relatively little stress
- Almost no stress at all

28) Have YOU ever been diagnosed with Mild Cognitive Impairment (MCI).

- Yes
- No
- I don't know

29) Have YOU ever been diagnosed with Alzheimer's disease?

- Yes
- No
- I don't know

Everyday Cognition (Displayed to Participants as “My Study Partner’s Everyday Cognition”)

Task Introduction: On the next few screens you will be asked to rate YOUR STUDY PARTNER’S ability to perform certain tasks now, as compared to his/her ability to do these same tasks **10 years ago**. The information you provide will give us a more accurate, detailed picture of changes in your study partner’s ability to think, remember things, and solve problems.

Remember, it is especially important that you complete this questionnaire privately and not in consultation with your study partner in order for your answers to be valid.

Questionnaire Instructions:

Remember, it is especially important that you complete this questionnaire privately and not in consultation with your study partner in order for your answers to be valid.

1) Compared to 10 years ago, has there been any change in... YOUR STUDY PARTNER'S memory

	Better or no change	Questionable/ occasionally worse	Consistently a little worse	Consistently much worse	I don't know
Remembering a few shopping items without a list.	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Remembering things that happened recently (such as recent outings, events in the news).	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Recalling conversations a few days later.	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Remembering where he/she has placed objects.	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Repeating stories and/or questions.	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Remembering the current date or day of the week.	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Remembering he/she has already told someone something.	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Remembering appointments, meetings, or engagements.	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>

2) Compared to 10 years ago, has there been any change in... YOUR STUDY PARTNER'S language

	Better or no change	Questionable/ occasionally worse	Consistently a little worse	Consistently much worse	I don't know
Forgetting the names of objects.	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Verbally giving instructions to others.	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Finding the right words to use in a conversation.	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Communicating thoughts in a conversation.	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Following a story in a book or on TV.	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Understanding the point of what other people are trying to say.	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Remembering the meaning of common words.	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Describing a program he/she has watched on TV.	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Understanding spoken directions or instructions.	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>

3) Compared to 10 years ago, has there been any change in... YOUR STUDY PARTNER'S visual-spatial and perceptual abilities

	Better or no change	Questionable/ occasionally worse	Consistently a little worse	Consistently much worse	I don't know
Following a map to find a new location.	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Reading a map and helping with directions when someone else is driving.	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Finding his/her car in a parking lot.	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Finding his/her way back to a meeting spot in the mall or other location.	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Finding his/her way around a familiar neighborhood.	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Finding his/her way around a familiar store.	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Finding his/her way around a house visited many times.	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>

4) Compared to 10 years ago, has there been any change in... YOUR STUDY PARTNER'S executive functioning: planning

	Better or no change	Questionable/ occasionally worse	Consistently a little worse	Consistently much worse	I don't know
Planning a sequence of stops on a shopping trip.	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
The ability to anticipate weather changes and plan accordingly (i.e., bring a coat or umbrella).	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Developing a schedule in advance of anticipated events.	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Thinking things through before acting.	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Thinking ahead.	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>

5) Compared to 10 years ago, has there been any change in... YOUR STUDY PARTNER'S executive functioning: organization

	Better or no change	Questionable/ occasionally worse	Consistently a little worse	Consistently much worse	I don't know
Keeping living and work space organized.	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Balancing the checkbook without error.	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Keeping financial records organized.	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Prioritizing tasks by importance.	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Keeping mail and papers organized.	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Using an organized strategy to manage a medication schedule involving multiple medications.	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>

6) Compared to 10 years ago, has there been any change in... YOUR STUDY PARTNER'S executive functioning: divided attention

	Better or no change	Questionable/ occasionally worse	Consistently a little worse	Consistently much worse	I don't know
The ability to do two things at once.	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Returning to a task after being interrupted.	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
The ability to concentrate on a task without being distracted by external things in the environment.	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Cooking or working and talking at the same time.	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>

Caregiver Burden Module (Displayed to Participants as “Caregiver Experience”)

Task Introduction: This section is intended for individuals that are the primary caregiver for their Brain Health Registry study partner, because their study partner needs extra assistance, perhaps due to a disability, disease, illness, cognitive impairment, or old age.

On the next few screens we will determine whether or not you are a caregiver, and if so, we will ask you about your experiences as a caregiver, such as how challenging it has been, how much satisfaction you feel from taking care of your study partner, and whether your physical health has been impacted. The information you give is completely private and confidential.

This module was developed by the National Institute of Aging- funded Stress Measurement Network. For information on how the survey was developed, please visit stresscenter.ucsf.edu.

- 1) Are you the primary caregiver for YOUR STUDY PARTNER, who needs extra assistance due to a disability, condition, or illness?

We define a primary caregiver as the person who is primarily responsible for helping make medical care decisions, is emotionally invested in the person's care, and provides help with daily activities (almost daily). Daily caregiving activities may include helping with medical or therapeutic treatment, preparing meal, and/or helping with dressing and/or bathing. Caregivers may be caring for a loved with dementia, or be the parent to a child with development delays or burdensome health conditions, for example.

- Yes, I am a caregiver for MY STUDY PARTNER
- No, I am not a caregiver for MY STUDY PARTNER
- I am not a caregiver based on this definition, but I do help MY STUDY PARTNER with some health issues

Branch Logic: If “Are you the primary caregiver for a member of your family or close friend who needs extra assistance due to a disability...” **No Is Selected** then:

Because you do not identify as a primary caregiver for YOUR STUDY PARTNER, we have no more questions for you. If you become a primary caregiver at a later time, you will have the opportunity to let us know at a future visit.

Branch Logic: If “Are you the primary caregiver for YOUR STUDY PARTNER, who needs extra assistance due to a disability...” **Yes, I am a caregiver for MY STUDY PARTNER is selected** then:

OR “Are you the primary caregiver for YOUR STUDY PARTNER, who needs extra assistance due to a disability...” **I am not a caregiver based on this definition, but I do help MY STUDY PARTNER with some health issues is selected** then:

- 2) Are you the primary caregiver for more than one person?
 - Yes
 - No

Branch Logic: If “Are you the primary caregiver for YOUR STUDY PARTNER, who needs extra assistance due to a disability...” **Yes, I am a caregiver for MY STUDY PARTNER is selected** then:

OR “Are you the primary caregiver for YOUR STUDY PARTNER, who needs extra assistance due to a disability” ... **I am not a caregiver based on this definition, but I do help someone with some health issues is selected** then:

3) What is the primary condition that requires YOUR STUDY PARTNER to need your care? If YOUR STUDY PARTNER has multiple conditions, please select all that apply.

- Alzheimer's disease
- Mild Cognitive Impairment (MCI)
- Frontotemporal Dementia
- Other dementia (e.g. Vascular dementia, Dementia with Lewy Bodies)
- Brain disease that affects movement (e.g. Parkinson's, Huntington's, ALS, Motor Neuron Disease, Multiple Sclerosis)
- Epilepsy
- Autism
- Psychiatric illness (e.g. schizophrenia, depression, bipolar disorder, anxiety disorder)
- Intellectual Disability
- Brain-related Injury (e.g. tumor, stroke, traumatic brain injury)
- Cancer
- Diabetes
- Heart Disease
- Other Chronic Illness
- Physical Disability or Injury
- Age-Related Issues
- Other, please specify: _____

Branch Logic: If “Are you the primary caregiver for YOUR STUDY PARTNER, who needs extra assistance due to a disability...” **Yes, I am a caregiver for MY STUDY PARTNER is selected** then:

OR “Are you the primary caregiver for YOUR STUDY PARTNER, who needs extra assistance due to a disability” ... **I am not a caregiver based on this definition, but I do help someone with some health issues is selected** then:

- 4) For how long have you been caregiving? For example:
- 1 year, 3 months
 - 0 years, 7 months
 - 9 years, 0 months

Years _____

Months _____

Branch Logic: If “Are you the primary caregiver for YOUR STUDY PARTNER, who needs extra assistance due to a disability...” **Yes, I am a caregiver for MY STUDY PARTNER is selected** then:

OR “Are you the primary caregiver for YOUR STUDY PARTNER, who needs extra assistance due to a disability” ... **I am not a caregiver based on this definition, but I do help someone with some health issues is selected** then:

- 5) Do you live with YOUR STUDY PARTNER?

- Yes
- No

Branch Logic: If “Are you the primary caregiver for YOUR STUDY PARTNER, who needs extra assistance due to a disability...” **Yes, I am a caregiver for MY STUDY PARTNER is selected** then:OR “Are you the primary caregiver for YOUR STUDY PARTNER, who needs extra assistance due to a disability” ... **I am not a caregiver based on this definition, but I do help someone with some health issues is selected** then:

- 6) What is your employment status?

- Employed full-time
- Employed part-time
- Full-time student
- Part-time student
- Unemployed
- Retired

Branch Logic: If “Are you the primary caregiver for YOUR STUDY PARTNER, who needs extra assistance due to a disability...” **Yes, I am a caregiver for MY STUDY PARTNER is selected** then:

OR “Are you the primary caregiver for YOUR STUDY PARTNER, who needs extra assistance due to a disability” ... **I am not a caregiver based on this definition, but I do help someone with some health issues is selected** then:

- 7) Did you have to leave your paid job, cut down on your hours, or drop out of school due to your caregiving responsibilities?
- Yes
 - No

Branch Logic: If “Are you the primary caregiver for YOUR STUDY PARTNER, who needs extra assistance due to a disability...” **Yes, I am a caregiver for MY STUDY PARTNER is selected** then:

OR “Are you the primary caregiver for YOUR STUDY PARTNER, who needs extra assistance due to a disability” ... **I am not a caregiver based on this definition, but I do help someone with some health issues is selected** then:

- 8) In addition to your role as caregiver, how many hours per week do you work at a paid job or attend school? If you do not have a job or go to school, please write 0.

Branch Logic: If “Are you the primary caregiver for YOUR STUDY PARTNER, who needs extra assistance due to a disability...” **Yes, I am a caregiver for MY STUDY PARTNER is selected** then:

OR “Are you the primary caregiver for YOUR STUDY PARTNER, who needs extra assistance due to a disability” ... **I am not a caregiver based on this definition, but I do help someone with some health issues is selected** then:

- 9) How many hours per week do you spend caring for YOUR STUDY PARTNER? We know this may be difficult to estimate, just give your best guess. If this question is not relevant to you, please enter 0.

Branch Logic: If “Are you the primary caregiver for YOUR STUDY PARTNER, who needs extra assistance due to a disability...” **Yes, I am a caregiver for MY STUDY PARTNER is selected** then:

OR “Are you the primary caregiver for YOUR STUDY PARTNER, who needs extra assistance due to a disability” ... **I am not a caregiver based on this definition, but I do help someone with some health issues is selected** then:

10) The following is a list of problems people sometimes have. Please indicate if any of these problems have occurred for YOUR STUDY PARTNER during the past week. If so, how much has this bothered or upset YOU when it happened. Please read the description of the ratings carefully.

	Has it occurred in the past week?		How much has this bothered or upset you when it happened?					
	No	Yes	Not At All (0)	A Little (1)	Moderately (2)	Very Much (3)	Extremely (4)	Has NOT occurred in the past week
Asking the same question over and over	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Trouble remembering recent events (i.e. items in newspaper or TV)	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Trouble remembering significant past events	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Losing or misplacing things	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Forgetting what day it is	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Starting, but not finishing, things	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>

Branch Logic: If “Are you the primary caregiver for YOUR STUDY PARTNER, who needs extra assistance due to a disability...” **Yes, I am a caregiver for MY STUDY PARTNER is selected** then:

OR “Are you the primary caregiver for YOUR STUDY PARTNER, who needs extra assistance due to a disability” ... **I am not a caregiver based on this definition, but I do help someone with some health issues is selected** then:

11) Please indicate if any of these problems have occurred for YOUR STUDY PARTNER during the past week. If so, how much has this bothered or upset YOU when it happened. Please read the description of the ratings carefully.

	Has it occurred in the past week?		How much has this bothered or upset you when it happened?					
	No	Yes	Not At All (0)	A Little (1)	Moderately (2)	Very Much (3)	Extremely (4)	Has NOT occurred in the past week
Difficulty concentrating on a task	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Destroying property	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Doing things that embarrass you	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Waking you or other family members up at night	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Talking loudly and rapidly	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Appeared anxious or worried	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>

Branch Logic: If “Are you the primary caregiver for YOUR STUDY PARTNER, who needs extra assistance due to a disability...” **Yes, I am a caregiver for MY STUDY PARTNER is selected** then:

OR “Are you the primary caregiver for YOUR STUDY PARTNER, who needs extra assistance due to a disability” ... **I am not a caregiver based on this definition, but I do help someone with some health issues is selected** then:

12) Please indicate if any of these problems have occurred for YOUR STUDY PARTNER during the past week. If so, how much has this bothered or upset YOU when it happened. Please read the description of the ratings carefully.

	Has it occurred in the past week?		How much has this bothered or upset you when it happened?					
	No	Yes	Not At All (0)	A Little (1)	Moderately (2)	Very Much (3)	Extremely (4)	Has NOT occurred in the past week
Engaging in behavior that is potentially dangerous to self or others	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Threatened to hurt oneself	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Threatened to hurt others	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Aggressive to others verbally	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Appeared sad or depressed	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Expressing feelings of hopelessness or sadness about the future	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>

Branch Logic: If “Please indicate if any of these problems have occurred for YOUR STUDY PARTNER during the past week... Engaging in behavior that is potentially dangerous to self or others - Has it occurred in the past week? - **Yes Is Selected** then:

OR “Please indicate if any of these problems have occurred for YOUR STUDY PARTNER during the past week... Threatened to hurt oneself - Has it occurred in the past week? - **Yes Is Selected** then:

OR “Please indicate if any of these problems have occurred for YOUR STUDY PARTNER during the past week... Threatened to hurt others - Has it occurred in the past week?” - **Yes Is Selected** then:

Please note that your responses to this questionnaire may not be immediately reviewed by the Brain Health Registry staff. If you feel that your care recipient/study partner is experiencing a medical or psychiatric emergency, please contact 911.

In addition, we would like to provide the following resources to you, which may be helpful:

National Suicide Prevention Lifeline provides 24/7, free and confidential support for people in distress, prevention and crisis resources for you or your loved ones, and best practices for professionals.

<https://suicidepreventionlifeline.org>

1-800-273-8255

National Alliance on Mental Illness is the nation’s largest grassroots mental health organization dedicated to building better lives for the millions of Americans affected by mental illness.

<http://www.nami.org>

800-950-6264

Alzheimer’s Association Helpline provides reliable information and support to all those who need assistance. The 24/7 Helpline serves people with memory loss, caregivers, health care professionals and the public.

1-800-272-3900

NIH Alzheimer’s Disease Education and Referral Center compiles, archives, and disseminates information concerning Alzheimer’s disease for health professionals, people with AD and their families, and the public. <https://www.nia.nih.gov/alzheimers>

1-800-438-4380

Branch Logic: If “Are you the primary caregiver for YOUR STUDY PARTNER, who needs extra assistance due to a disability...” **Yes, I am a caregiver for MY STUDY PARTNER is selected** then:

OR “Are you the primary caregiver for YOUR STUDY PARTNER, who needs extra assistance due to a disability” ... **I am not a caregiver based on this definition, but I do help someone with some health issues is selected** then:

13) Please indicate if any of these problems have occurred for YOUR STUDY PARTNER during the past week. If so, how much has this bothered or upset YOU when it happened. Please read the description of the ratings carefully.

	Has it occurred in the past week?		How much has this bothered or upset you when it happened?					
	No	Yes	Not At All (0)	A Little (1)	Moderately (2)	Very Much (3)	Extremely (4)	Has NOT occurred in the past week
Crying and tearfulness	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Commenting about death of self or others	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Talking about feeling lonely	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Comments about feeling worthless or being a burden to others	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Comments about feeling like a failure, or about not having any worthwhile accomplishments in life	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Arguing, irritability, and/or complaining	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>

Branch Logic: If “Are you the primary caregiver for YOUR STUDY PARTNER, who needs extra assistance due to a disability...” **Yes, I am a caregiver for MY STUDY PARTNER is selected** then:

OR “Are you the primary caregiver for YOUR STUDY PARTNER, who needs extra assistance due to a disability” ... **I am not a caregiver based on this definition, but I do help someone with some health issues is selected** then:

14) As a caregiver do YOU feel...

	Never (0)	Rarely (1)	Sometimes (2)	Quite Frequently (3)	Nearly Always (4)
That because of the time you spend caregiving that you don't have enough time for yourself?	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Stressed between caregiving and trying to meet other responsibilities (work/family)?	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Angry when you are around YOUR STUDY PARTNER?	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
That YOUR STUDY PARTNER currently affects your relationship with family members in a negative way?	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Strained when you are around YOUR STUDY PARTNER?	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
That your health has suffered because of caregiving?	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>

Branch Logic: If “Are you the primary caregiver for YOUR STUDY PARTNER, who needs extra assistance due to a disability...” **Yes, I am a caregiver for MY STUDY PARTNER is selected** then:

OR “Are you the primary caregiver for YOUR STUDY PARTNER, who needs extra assistance due to a disability” ... **I am not a caregiver based on this definition, but I do help someone with some health issues is selected** then:

15) As a caregiver do YOU feel...

	Never (0)	Rarely (1)	Sometimes (2)	Quite Frequently (3)	Nearly Always (4)
That you don't have as much privacy as you would like because of caregiving?	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
That your social life has suffered because you are caring for YOUR STUDY PARTNER?	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
That you have lost control of your life since you began providing care for YOUR STUDY PARTNER?	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Uncertain about what to do about YOUR STUDY PARTNER?	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
You should be doing more for YOUR STUDY PARTNER?	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
You could do a better job caring for YOUR STUDY PARTNER?	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>

Branch Logic: If “Are you the primary caregiver for YOUR STUDY PARTNER, who needs extra assistance due to a disability...” **Yes, I am a caregiver for MY STUDY PARTNER is selected** then:

OR “Are you the primary caregiver for YOUR STUDY PARTNER, who needs extra assistance due to a disability” ... **I am not a caregiver based on this definition, but I do help someone with some health issues is selected** then:

16) As a caregiver, do YOU feel...

	Never (0)	Rarely (1)	Sometimes (2)	Quite Frequently (3)	Nearly Always (4)
I'm not getting enough sleep	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
My health has suffered	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Caregiving has made me physically sick	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
I'm physically tired	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
I have headaches or other pains	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>

Branch Logic: If “Are you the primary caregiver for YOUR STUDY PARTNER, who needs extra assistance due to a disability...” **Yes, I am a caregiver for MY STUDY PARTNER is selected** then:

OR “Are you the primary caregiver for YOUR STUDY PARTNER, who needs extra assistance due to a disability” ... **I am not a caregiver based on this definition, but I do help someone with some health issues is selected** then:

17) As a caregiver do YOU feel...

Select the response that best describes YOUR life.

	Strongly disagree (1)	Disagree (2)	Neither agree nor disagree (3)	Agree (4)	Strongly Agree (5)
I wish I were free to lead a life of my own	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
I feel trapped by MY STUDY PARTNER'S condition	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
I wish I could just run away	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>

Branch Logic: If “Are you the primary caregiver for YOUR STUDY PARTNER, who needs extra assistance due to a disability...” **Yes, I am a caregiver for MY STUDY PARTNER is selected** then:

OR “Are you the primary caregiver for YOUR STUDY PARTNER, who needs extra assistance due to a disability” ... **I am not a caregiver based on this definition, but I do help someone with some health issues is selected** then:

18) As a caregiver do YOU feel... Select the response that best describes YOUR life.

	Strongly disagree (1)	Disagree (2)	Neither agree nor disagree (3)	Agree (4)	Strongly agree (5)
Caring for MY STUDY PARTNER is important to me	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
I enjoy caring for MY STUDY PARTNER	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Caring for MY STUDY PARTNER makes me feel good	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
I feel privileged to care for MY STUDY PARTNER	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
I resent having to care for MY STUDY PARTNER	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
I really want to care for MY STUDY PARTNER	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Nothing I do seems to please MY STUDY PARTNER	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
MY STUDY PARTNER'S pleasure over little things gives me pleasure	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>

Branch Logic: If “Are you the primary caregiver for YOUR STUDY PARTNER, who needs extra assistance due to a disability...” **Yes, I am a caregiver for MY STUDY PARTNER is selected** then:

OR “Are you the primary caregiver for YOUR STUDY PARTNER, who needs extra assistance due to a disability” ... **I am not a caregiver based on this definition, but I do help someone with some health issues is selected** then:

19) Select the response that best describes your life.

	Strongly disagree (1)	Disagree (2)	Neither agree nor disagree (3)	Agree (4)	Strongly agree (5)
The things I do to take care of MY STUDY PARTNER are worthwhile	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Most of my caregiving activities seem trivial and unimportant	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
There is great value in what I do everyday for MY STUDY PARTNER	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Being a caregiver is an important role to me	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
I criticize myself for having negative emotions about having to be a caregiver	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>

Branch Logic: If “Are you the primary caregiver for YOUR STUDY PARTNER, who needs extra assistance due to a disability...” **Yes, I am a caregiver for MY STUDY PARTNER is selected** then:

OR “Are you the primary caregiver for YOUR STUDY PARTNER, who needs extra assistance due to a disability” ... **I am not a caregiver based on this definition, but I do help someone with some health issues is selected** then:

20) Select the response that best describes your life.

	Strongly disagree (1)	Disagree (2)	Neither agree nor disagree (3)	Agree (4)	Strongly agree (5)
I tell myself I shouldn't be thinking or feeling the way I am about being a caregiver	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
I accept my negative feelings about caregiving, instead of pushing them away	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Being a caregiver prevents me from having a fulfilling life	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
I am able to be happy and satisfied with my life, and be a caregiver	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
I am at peace about leading a life as a caregiver	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>

Branch Logic: If “Are you the primary caregiver for YOUR STUDY PARTNER, who needs extra assistance due to a disability...” **Yes, I am a caregiver for MY STUDY PARTNER is selected** then:

OR “Are you the primary caregiver for YOUR STUDY PARTNER, who needs extra assistance due to a disability” ... **I am not a caregiver based on this definition, but I do help someone with some health issues is selected** then:

21) As a result of being a caregiver, I have experienced the following changes in my life:

	Strongly disagree (1)	Disagree (2)	Neither agree nor disagree (3)	Agree (4)	Strongly agree (5)
I changed my priorities about what is important in life	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
I have a greater sense of closeness with others	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
I established a new path for my life	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
I discovered that I was stronger than I thought I was	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
I have a stronger religious faith	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>

Join the Brain Health Registry

Task Introduction: Thank you for participating in the Brain Health Registry Study Partner Portal. By lending your unique and powerful voice to this initiative, you are helping us to revolutionize brain health research.

If you are interested in doing more expanding your involvement in our study, we invite you to become a primary participant in the larger main Brain Health Registry research project. As a participant, you will have the opportunity to answer more questions –this time about your own health and lifestyle—, about your own health and lifestyle, and to take online brain tests. Please know that becoming a participant in the Brain Health Registry is separate from your role as a Study Partner and is completely optional.

The Brain Health Registry is open to everyone 18 years or older. You do not need to have a brain disease or disorder to qualify for participation.

We encourage you to visit our website, www.brainhealthregistry.org for information, including what it means to be a Brain Health Registry participant, what is expected of participants and how to enroll.

[Join Now]

Functional Activities (Displayed as “My Study Partner’s Day-to-Day Life”)

Task Introduction: In this questionnaire, you will be asked to select the most accurate representation of YOUR STUDY PARTNER'S level of ability to perform each activity over the preceding four weeks. The information you provide will give us a more complete picture of YOUR STUDY PARTNER'S current ability to perform everyday tasks, important indicators of brain health that are often very meaningful to individuals and their loved ones.

Remember, it is especially important that you complete this questionnaire privately and not in consultation with your study partner in order for your answers to be valid.

Questionnaire Instructions:

Select the most accurate representation of YOUR STUDY PARTNER’S level of ability to perform each activity over the preceding four weeks.

- 1) Writing checks, paying bills, or balancing checkbook.
 - Normal
 - Never did, but could now do
 - Never did, would have difficulty now
 - Has difficulty, but does by self
 - Requires assistance
 - Dependent a

- 2) Assembling tax records, business affairs, or other papers.
 - Normal
 - Never did, but could now do
 - Never did, would have difficulty now
 - Has difficulty, but does by self
 - Requires assistance
 - Dependent

- 3) Shopping alone for clothes, household necessities, or groceries.
 - Normal
 - Never did, but could now do
 - Never did, would have difficulty now
 - Has difficulty, but does by self
 - Requires assistance
 - Dependent

- 4) Playing a game of skill such as bridge or chess, working on a hobby.
 - Normal
 - Never did, but could now do
 - Never did, would have difficulty now

- Has difficulty, but does by self
 - Requires assistance
 - Dependent
- 5) Heating water, making a cup of coffee, turning off the stove.
- Normal
 - Never did, but could now do
 - Never did, would have difficulty now
 - Has difficulty, but does by self
 - Requires assistance
 - Dependent
- 6) Preparing a balanced meal.
- Normal
 - Never did, but could now do
 - Never did, would have difficulty now
 - Has difficulty, but does by self
 - Requires assistance
 - Dependent
- 7) Keeping track of current events.
- Normal
 - Never did, but could now do
 - Never did, would have difficulty now
 - Has difficulty, but does by self
 - Requires assistance
 - Dependent
- 8) Paying attention to and understanding a TV program, book, or magazine.
- Normal
 - Never did, but could now do
 - Never did, would have difficulty now
 - Has difficulty, but does by self
 - Requires assistance
 - Dependent
- 9) Remembering appointments, family occasions, holidays, medications.
- Normal
 - Never did, but could now do
 - Never did, would have difficulty now
 - Has difficulty, but does by self

- Requires assistance
- Dependent

10) Traveling out of the neighborhood, driving, or arranging to take public transportation.

- Normal
- Never did, but could now do
- Never did, would have difficulty now
- Has difficulty, but does by self
- Requires assistance