Brain Health Registry Copy of Questionnaires for Study Partners

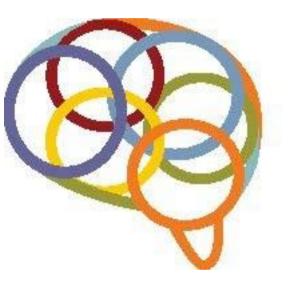


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Profile Questionnaire

1) Month/Year of Birth

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

-		
2)	Gender O	Male
	O	Female
3)⊦	landedn	
		Right
		Left
	0	Ambidextrous
4)	What is	s the highest level of education you have completed?
	\mathbf{O}	Grammar School
		High School / GED
		Some College
		2-year College Degree
		4-year College Degree
		Masters Degree
		Doctoral Degree
	3	Professional Degree (JD, MD)
5)	Ethnicit	V.
٦)	_	y Latino
		Not Latino
		Decline to State
6)	Race (Se	elect all that apply)
- /	-	African American
		Asian
	O	Caucasian
	O	Native American
	O	Pacific Islander
	\mathbf{O}	Other
	O	Declined to State
7)	Locatio	
	there a	g where our Brain Health Registry participants live is important. It helps us determine if re additional study opportunities available in your area. If you prefer to not give your
	address	s, 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 trials? O Yes O No	clinical
9)	We send email new sletters to our members with updates on the Brain Health Registry. We these NO MORE THAN once a month.	send
	☐ 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]? O Spouse O Sibling O Parent O Son or Daughter O Son or Daughter In-Law **O** Grandparent O Grandchild O Other Relative O Friend **O** Roommate O Paid Caregiver 2) How long have you known _____ [PARTICIPANT'S FIRST NAME]? 3) Do you and _____ [PARTICIPANT'S FIRST NAME] currently live together? O Yes O 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")

<u>Task Introduction</u>: 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 <u>not in consultation with your study partner</u> 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.

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?

O	Yes
	No
O	I don't know
2) Has there be	en a change in YOUR STUDY PARTNER'S memory in the past 10 years?
	Yes
	No
O	I don't know
3) Does YOUR S	STUDY PARTNER have trouble remembering whether he/she told someone something?
	Yes
	No
O	I don't know
Please answer	the following questions about YOUR STUDY PARTNER, thinking about his or her ability to
perform certain	n tasks as <u>compared to one year ago</u> . 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 \	OUR STUDY PARTNER has had a significant decline in memory compared to one year ago?
0	Yes
O	Maybe
0	No
5) <u>Compared to</u>	o one year ago, does YOUR STUDY PARTNER tend to ask the same question over and over?
O	Yes
O	Maybe
O	No
6) <u>Compared to</u>	o one year ago, has YOUR STUDY PARTNER been misplacing things more often?
O	Yes
O	Maybe
O	No

7) Compared to	one year ago, does it seem to you that lately YOUR STUDY PARTNER is relying more on
written remind	ers (e.g., shopping lists, calendars)?
\circ	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?
Q	Yes
	Maybe
	No
9) Compared to	one year ago, does YOUR STUDY PARTNER have trouble recalling names, finding the right
•	eting sentences?
•	
	Yes
	Maybe
3	No
10) <u>Compared t</u>	to one year ago, is YOUR STUDY PARTNER having more trouble driving? (e.g., does he/she
drive more slov	vly, have more trouble at night, tend to get lost, have accidents?)
O	Yes
	Maybe
	No
11) Compared t	to one year ago, is YOUR STUDY PARTNER having more difficulty managing money (e.g.,
	culating change, completing tax forms)?
	Yes
_	Maybe
9	No
12) <i>Compared</i>	to one year ago, is YOUR STUDY PARTNER less interested in social activities?
\circ	Yes
	Maybe
	No
13) Do you beli	eve, based on your own observations or comments from YOUR STUDY PARTNER'S co-
workers, that Y	OUR STUDY PARTNER'S work performance (paid of volunteer) had declined significantly,
compared to or	<u>ne year ago</u> ?
\circ	Yes
	Maybe
	No

14) Does YOUR STUDY PARTNER have more trouble following the news, or the plots of books, movies or

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TV shows, compared to one year ago?

	Yes Maybe
	No
	ny activities (e.g., hobbies, such as card games, crafts) that are substantially more difficult ARTNER now <u>compared to one year ago</u> ?
	Yes
	Maybe No
	to one year ago, is YOUR STUDY PARTNER more likely to become disoriented, or get lost,
for example wh	en traveling to another city?
	Yes
	Maybe No
	to one year ago, does YOUR STUDY PARTNER have more difficulty using household
appliances (suc	h as the washing machine, VCR or computer)?
	Yes
	Maybe No
18) Has YOUR S	TUDY PARTNER ever been diagnosed with Mild Cognitive Impairment (MCI)?
O	Yes
	No I don't know
•	T don't know
19) Has YOUR S	TUDY 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 cor	cerned that YOU have a memory problem?
O	Yes
•	No
21) Do YOU hav	ve trouble remembering if YOU have already told someone something?
	Yes
O	No

22) Compared t	to <u>10 years ago</u> , would you say that there has been a change in YOUR memory?
O	Yes
•	No
23) In general,	would you say YOUR health is:
•	Excellent
•	Very Good
•	Good
	Fair
0	Poor
24) Compared t	to one year ago, how would you rate YOUR health in general now?
O	Much Better
•	Better
•	Same
•	Worse
O	Much Worse
25) Over <u>the las</u>	st two months, how often have YOU been bothered by having little interest or pleasure in
doing things?	
O	Not at all
	Several Days
	More than half the days
0	Nearly every day
26) Over the las	st two months, how often have YOU been bothered by feeling down, depressed, or
hopeless?	, , , , , , , , , , , , , , , , , , ,
Q	Not at all
	Several Days
	More than half the days
	Nearly every day
27) Strass mazi	ns a situation in which a person feels tense, restless, nervous or anxious or is unable to sleep
•	e his/her mind is troubled all the time. During the past 12 months, would you say YOU
experienced:	e his/her mind is troubled an the time. During the past 12 months, would you say 100
O	A lot of stress
O	A moderate amount of stress
	Relatively little stress
0	Almost no stress at all
28) Have YOU e	ever been diagnosed with Mild Cognitive Impairment (MCI).
\circ	Yes
	No
	I don't know

29) Have YOU e	ver been diagnosed with Alzheimer's disease
•	Yes
O	No
O	I don't know

Everyday Cognition (Displayed to Participants as "My Study Partner's Everyday Cognition")

<u>Task Introduction</u>: 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 <u>not in</u> 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 <u>not in consultation with your study partner</u> 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.	•	•	•	•	O
Remembering things that happened recently (such as recent outings, events in the news).	•	•	O	•	O
Recalling conversations a few days later.	0	•	•	0	O
Remembering where he/she has placed objects.	0	•	•	0	O
Repeating stories and/or questions.	0	•	0	0	O
Remembering the current date or day of the week.	•	0	0	0	O
Remembering he/she has already told someone something.	•	•	•	•	O
Remembering appointments, meetings, or engagements.	•	•	•	•	•

2) Compared to <u>10 years ago</u>, 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.	•	•	0	0	O
Verbally giving instructions to others.	0	•	0	0	O
Finding the right words to use in a conversation.	•	•	•	•	O
Communicating thoughts in a conversation.	•	•	•	•	O
Following a story in a book or on TV.	•	•	0	0	O
Understanding the point of what other people are trying to say.	•	•	•	•	•
Remembering the meaning of common words.	•	•	•	•	O
Describing a program he/she has watched on TV.	•	•	•	•	O
Understanding spoken directions or instructions.	•	•	•	•	O

3) Compared to <u>10 years ago</u>, 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.	•	•	•	•	O
Reading a map and helping with directions when someone else is driving.	•	•	•	•	O
Finding his/her car in a parking lot.	•	0	•	•	O
Finding his/her way back to a meeting spot in the mall or other location.	•	0	•	•	O
Finding his/her way around a familiar neighborhood.	•	0	•	•	O
Finding his/her way around a familiar store.	0	•	•	•	O
Finding his/her way around a house visited many times.	O	•	0	•	O

4) Compared to <u>10 years ago</u>, 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.	0	0	0	•	0
The ability to anticipate weather changes and plan accordingly (i.e., bring a coat or umbrella).	•	•	0	•	•
Developing a schedule in advance of anticipated events.	advance of anticipated O		•	0	•
Thinking things through before acting.	•	0	0	•	0
Thinking ahead.	0	0	0	0	O

5) Compared to <u>10 years ago</u>, 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.	•	0	•	•	O	
Balancing the checkbook without error.	•	0	0	•	O	
Keeping financial records organized.	•	0	0	•	O	
Prioritizing tasks by importance.	•	0	0	•	O	
Keeping mail and papers organized.	•	0	0	•	O	
Using an organized strategy to manage a medication schedule involving multiple medications.	•	•	•	•	•	

6) Compared to <u>10 years ago</u>, 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.	0	0	0	0	•
Returning to a task after being interrupted.	0	0	•	•	•
The ability to concentrate on a task without being distracted by external things in the environment.	•	•	•	•	•
Cooking or working and talking at the same time.	0	0	0	0	0

Caregiver Burden Module (Displayed to Participants as "Caregiver Experience")

<u>Task Introduction</u>: 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
- O No, I am not a caregiver for MY STUDY PARTNER
- O 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					person?

- O Yes
- O No

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)	٧	Vhat is the primary condition that requires YOUR STUDY PARTNER to need your care? If YOUR
	S	TUDY 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
	1	Other, please specify:

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:

issues is selected them.
 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?
3) Do you live with 100K 310D11 AKTNEK:
O Yes
O No
Durant Lania If "Annual the gring and are in a few VOLID CTUDY DADTNED with a read out of a reinforce
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?
O Employed full-time
O Employed part-time
O Full-time student
O Part-time student
O Unemployed
O Retired

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 you	r
	caregiving responsibilities?	
	O Yes	
	O 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 o
	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.

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.

	in the	ccurred e past ek?	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	0	0	•	•	•	•	0	•
Trouble remembering recent events (i.e. items in newspaper or TV)	O	0	0	0	•	0	0	0
Trouble remembering significant past events	•	•	•	•	•	•	O	0
Losing or misplacing things	O	O	O	•	0	•	•	•
Forgetting what day it is	O	O	O	O	•	O	0	O
Starting, but not finishing, things	O	O	O	O	•	O	0	0

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.

	in the	ccurred e past ek?	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	•	0	0	•	•	•	O	•
Destroying property	•	•	O	O	0	O	0	0
Doing things that embarrass you	•	O	•	O	0	0	0	O
Waking you or other family members up at night	•	•	•	•	•	•	O	O
Talking loudly and rapidly	O	O	O	O	•	O	0	0
Appeared anxious or worried	•	O	O	0	0	0	0	O

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?				appened?	
	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	O	0	O	O	•	0	•	0
Threatened to hurt oneself	O	•	0	0	0	•	0	0
Threatened to hurt others	O	•	0	0	0	•	0	0
Aggressive to others verbally	O	•	•	O	0	•	O	•
Appeared sad or depressed	O	•	O	O	0	0	•	0
Expressing feelings of hopelessness or sadness about the future	•	•	•	•	•	•	0	0

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

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?		in the past How much has this bothered or upset you when it has			nappened?		
	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	O	O	0	0	0	0	O	•
Commenting about death of self or others	O	O	O	O	0	O	0	0
Talking about feeling lonely	O	O	O	O	0	O	0	0
Comments about feeling worthless or being a burden to others	•	O	•	•	0	•	O	•
Comments about feeling like a failure, or about not having any worthwhile accomplishments in life	•	•	O	O	0	O	O	O
Arguing, irritability, and/or complaining	O	O	O	O	•	O	0	•

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?	•	•	•	•	•
Stressed between caregiving and trying to meet other responsibilities (work/family)?	•	•	•	•	•
Angry when you are around YOUR STUDY PARTNER?	0	•	•	•	•
That YOUR STUDY PARTNER currently affects your relationship with family members in a negative way?	•	O	•	•	•
Strained when you are around YOUR STUDY PARTNER?	0	0	0	0	0
That your health has suffered because of caregiving?	•	O	0	•	•

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?	•	•	•	0	•
That your social life has suffered because you are caring for YOUR STUDY PARTNER?	0	•	•	•	•
That you have lost control of your life since you began providing care for YOUR STUDY PARTNER?	•	•	0	0	0
Uncertain about what to do about YOUR STUDY PARTNER?	0	•	0	0	0
You should be doing more for YOUR STUDY PARTNER?	0	0	•	•	•
You could do a better job caring for YOUR STUDY PARTNER?	•	0	0	•	•

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	•	•	0	0	•
My health has suffered	•	•	•	0	•
Caregiving has made me physically sick	0	0	0	0	0
I'm physically tired	•	•	•	0	•
I have headaches or other pains	•	•	•	•	•

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	•	•	0	•	•
I feel trapped by MY STUDY PARTNER'S condition	•	•	0	•	0
I wish I could just run away	•	•	•	•	•

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	•	•	•	•	o
I enjoy caring for MY STUDY PARTNER	•	0	0	0	O
Caring for MY STUDY PARTNER makes me feel good	O	•	0	•	•
I feel privileged to care for MY STUDY PARTNER	0	0	•	•	0
I resent having to care for MY STUDY PARTNER	0	0	•	•	0
I really want to care for MY STUDY PARTNER	0	0	•	•	O
Nothing I do seems to please MY STUDY PARTNER	O	•	0	•	•
MY STUDY PARTNER'S pleasure over little things gives me pleasure	O	0	•	•	O

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	•	•	•	•	•
Most of my caregiving activities seem trivial and unimportant	0	•	•	•	0
There is great value in what I do everyday for MY STUDY PARTNER	0	•	•	•	•
Being a caregiver is an important role to me	•	0	0	•	O
I criticize myself for having negative emotions about having to be a caregiver	0	•	•	•	•

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	0	0	•	•	•
I accept my negative feelings about caregiving, instead of pushing them away	O	O	•	•	•
Being a caregiver prevents me from having a fulfilling life	0	•	0	0	O
I am able to be happy and satisfied with my life, and be a caregiver	0	•	0	0	•
I am at peace about leading a life as a caregiver	O	•	0	0	0

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	•	•	•	•	•
I have a greater sense of closeness with others	•	•	•	•	•
I established a new path for my life	•	•	•	•	•
I discovered that I was stronger than I thought I was	0	0	0	0	0
I have a stronger religious faith	•	•	•	•	•

Join the Brain Health Registry

<u>Task Introduction</u>: 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")

<u>Task Introduction</u>: 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:

O Normal

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

		Never did, but could now do Never did, would have difficulty now
	•	Has difficulty, but does by self
	•	Requires assistance
	0	Dependent a
2)	Assemi	oling tax records, business affairs, or other papers.
-,	O	Normal
	_	Never did, but could now do
		Never did, would have difficulty now
		Has difficulty, but does by self
		Requires assistance
		Dependent
3)	Shoppi	ng alone for clothes, household necessities, or groceries.
	O	Normal
	O	Never did, but could now do
	•	Never did, would have difficulty now
	O	Has difficulty, but does by self
	O	Requires assistance
	O	Dependent
4)	Playing	a game of skill such as bridge or chess, working on a hobby.
•		Normal
	0	Never did, but could now do
		Never did, would have difficulty now

1) Writing checks, paying bills, or balancing checkbook.

	O	Has difficulty, but does by self
	O	Requires assistance
	O	Dependent
-,		
5)	-	g 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
	3	Dependent
6)	Prepari	ng a balanced meal.
	\mathbf{C}	Normal
	•	Never did, but could now do
	•	Never did, would have difficulty now
	•	Has difficulty, but does by self
	\mathbf{C}	Requires assistance
	0	Dependent
7)		g 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
	0	Dependent
0)	Doving	attention to and understanding a TV program, hook or magazine
8)		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
	0	Dependent
	•	Dependent
9)		bering appointments, family occasions, holidays, medications.
		Normal
		Never did, but could now do
		Never did, would have difficulty now
	O	Has difficulty, but does by self

	O O	Requires assistance Dependent
10) Traveling out of the neighborhood, driving, or arranging to take public transportation.		
	\mathbf{C}	Normal
	\mathbf{O}	Never did, but could now do
	\mathbf{C}	Never did, would have difficulty now
	\mathbf{O}	Has difficulty, but does by self
	\mathbf{O}	Requires assistance