



Co-Enrollment Program

Suggested Recruitment Materials (Collaborator to Participant)

These materials are provided as reference for the collaborator. The collaborator can choose to use whatever materials work for their study. Please note that all recruitment materials will need to be submitted to in the collaborator's IRB submission.

General Brain Health Registry Talking Points

The information below will help answer questions commonly asked by individuals who are interested in participating in the Brain Health Registry (BHR). Additional information can be found on the BHR website: www.brainhealthregistry.org

Please note that certain answers may be updated by the collaborator to be study specific.

What is the Brain Health Registry?

- The Brain Health Registry is a free, online research registry for adult volunteers who want to participate in neuroscience research, and help speed the path to treatments for conditions like Alzheimer's and other brain diseases.
- The Brain Health Registry is led by researchers at the UCSF. The Principal investigator is Dr. Michael Weiner, Professor of Radiology and Biomedical Engineering, Medicine, Psychiatry and Neurology at UCSF. Dr. Scott Mackin, a neuropsychologist and UCSF Associate Professor of Psychiatry, and Dr. Rachel Nosheny, a neuroscientist, are co-investigators.
- **Optional if co-enrolled participants can be referred to another study:** *The Brain Health Registry uses the internet to collect information on health, lifestyle, and brain function from our participants. This information or data helps determine volunteers who may be eligible for other research studies and/or clinical trials. In doing this the Brain Health Registry is building a large pool of volunteers who can be matched and referred to participate in other research studies.*
- Matching BHR participants to other research studies is important because the discovery of new medications is often delayed by the various challenges of recruiting for clinical trials. If we can help eligible people get into the right research studies, we can accelerate the drug discovery process.
- The Brain Health Registry is the first neuroscience project to leverage the internet in this way and on this large scale. This study will provide valuable insights about whether brain health information collected online can tell us the same thing as information collected in clinical settings. This knowledge can then be used to design the best assessments for future research studies.
- The Brain Health Registry is an observational research study. It is not a treatment trial. So it gives you the opportunity to be involved in research, without ever coming in to a clinic, even if you are not interested in or eligible for a clinical trial.
- The Brain Health Registry does not provide clinical advice or clinical information.

Who can join the Brain Health Registry?

- Participants must have access to the internet using a desktop or laptop computer, tablet, or smart phone. You do not need to have a computer or device in your home. You just need access to the internet for visits every few months.
- Some brain tests require a desktop or laptop computer, but you can still participate in all other tasks using another device.
- Questionnaires are accessible by all devices.

- Email is the primary way that Brain Health Registry study staff communicates with participants; therefore you must have a working email address that you regularly use to enroll in this study.
- Participants will also have the opportunity to invite a study partner to participate in the Brain Health Registry with them. Study Partners must be 18 or older, have a working email address, and access to internet at 6-month intervals.

What is a Study Partner, why do I need one, and what do they do?

- A study partner is someone who knows a participant well, such as a caregiver, family member, or friend, and can answer questions about the participant's memory, health and day-to-day activities.
- Study partners have a unique and powerful voice and having the pair of you participate in the Brain Health Registry helps researcher obtain a more complete understanding of cognition and everyday function.
- Participants do not have to have a Study Partner to participate in the Brain Health Registry.
- Study partners will go to the website and once they agree to an Informed Consent Form, they will answer questions about themselves and about the participant. They may also be asked to complete brain tests.

Are there costs or payment to join the Brain Health Registry?

- There is no cost to join.
- *Participants/Study Partners will not be paid. / Or will be compensated by <COLLABORATOR study name> Study.*
- The Brain Health Registry is relying on volunteers to participate in this project.

What is the connection to UCSF?

- The Brain Health Registry is led by UCSF researchers and is a research study overseen by UCSF Institutional Review Board (IRB) or ethics board.
- This means that everything that the Brain Health Registry does is first reviewed and approved by the UCSF IRB.

What does it mean to participate in the Brain Health Registry?

- Participation is done entirely online at www.brainhealthregistry.org.
- Once enrolled, participants answer some questions about their general health, lifestyle, family history of Alzheimer's disease, and willingness to participate in additional research studies.
- Participants also take online tests (which are sort of like games) that assess memory, thinking and other brain function.
- Participants are asked to return to the BHR website every few months to answer follow-up questions and retake brain tests.
- It takes most people a few minutes to sign-up and about <TIME> minutes/hour(s) per year to participate.
- Participants do not have to complete study tasks in one sitting. Participants can stop and complete study tasks when it is convenient. Participants can also complete study tasks in whatever order they'd like.

What do I have to do to join?

- Register for the Brain Health Registry at www.brainhealthregistry.org. It's easy and takes a few minutes.
- Give some basic information about yourself: your name, email address, and date of birth.
- Participants must agree to the informed consent form.
- Participation in research is voluntary and you are able to withdraw your participation from the Brain Health Registry at any time.

What is an informed consent form and why is this required?

- The Brain Health Registry is a UCSF research study therefore the UCSF IRB or ethics board requires that they obtain consent from all individuals participating in this research project.
- The consent form outlines the study in detail and lets you know your role and your rights as a research participant.

- The consent also lets you know that data collected under the Brain Health Registry study protocol will be shared with the <COLLABORATOR study name> Study research team, this so Brain Health Registry scientists and <COLLABORATOR study name> researchers can better study the brain health

What happens after I join the Brain Health Registry?

- Participants complete online study tasks (questionnaires and brain tests). These vary in length, but you don't have to do them all at once.
- The Brain Health Registry sends a maximum of 3 reminder emails if participants do not complete study tasks.
- Participants can complete study tasks in any order.
- The Brain Health Registry emails participants and asks that they return to the website every <TIME> minutes/hour(s) to do follow-up questionnaires and retake brain tests.

What if I am not familiar with using/able to use a computer, can someone help me?

- Participation in the BHR is entirely online, but if you need someone to help you register and answer questions, that's okay.
- However, brain tests have to be completed by you. Brain Health Registry participants have to take brain tests on their own, without any assistance.
- If you can't do the brain tests, you can still participate by filling out the questionnaires.

I only have an iPad/tablet/smartphone, can I still participate?

- Of course! However at this time some brain tests cannot be completed on mobile devices, as they require Adobe Flash Player.
- In this case you can return to the BHR website from a desktop or laptop computer and complete brain tests at a later time.
- Please remember, participants do not have to complete all of the brain tests to be involved in the Brain Health Registry.

What is my information used for?

- The Brain Health Registry study staff will use information collected from participants for research purposes. They will share participant data with the <COLLABORATOR study name> Study research team to create a more informative, enriched dataset.
- Research results may be presented in scientific conferences and published in scientific journals. In the event this occurs, presentations and publications will never include any information that could identify participants, in any way.
- **Optional if co-enrolled participants can be referred to another study:** *The Brain Health Registry study staff will also use information collected from willing participants to identify potential volunteers for other research studies and/or clinical trials. The Brain Health Registry will only let participants know about additional research opportunities that they think participants may be eligible for and are interested in.*
- **Optional if co-enrolled participants can be referred to another study:** *The Brain Health Registry will only refer participants to other research studies if they have agreed to receive information about additional research opportunities.*
- **Optional if co-enrolled participants can be referred to another study:** *Participation in all research is voluntary. The choice to participate, or not participate, in additional research studies will not affect participation in the Brain Health Registry.*

Is my information secure?

- All information entered in the Brain Health Registry is secure and only accessible by Brain Health Registry study staff. The Brain Health Registry only uses data for the purposes stated in our consent form and privacy statement. The privacy statement is publicly available at www.brainhealthregistry.org/privacy.
- Information about Brain Health Registry participants will be shared with the <COLLABORATOR study name>.

- If the Brain Health Registry ever would like to share identifying information with another research group, the Brain Health Registry will ask for explicit permission first, and will only share identifying information for those who have agreed.

What if I am not comfortable giving some information?

- That's okay! Participants do not have to answer every question.
- Participants do not have to complete every questionnaire to participate in the Brain Health Registry.

Will I get results from the cognitive tests?

- NO. At this time, Brain Health Registry researchers are NOT providing results to participants but are exploring this as a future option.
- The reason for this is that the brain tests are not designed as diagnostic assessments and although helpful for our research, they should not be used as the basis of any medical or any other decisions.

What do I get in return?

- As a participant in the Brain Health Registry you will be contributing to a large, observation study that may accelerate the discovery of treatment for Alzheimer's and other brain diseases.
- You will receive regular e-newsletters from the Brain Health Registry study team every 2 or 3 months. Newsletters will provide information on the latest brain health research as well as resources for caregivers and those with memory concerns.

What if I am already a participant in the Brain Health Registry?

- Not a problem. We thank you for your participation and ask that you re-register so the Brain Health Registry study team knows you are also in the <COLLABORATOR study name> study.
- They will send you an email with instruction on how to do this.

If I interested in participating today, does that mean I am enrolled in the Brain Health Registry?

No. If you <next steps for study specific registration process> today, you will then receive an email from researchers at the University of California, San Francisco with more information and link to the Brain Health Registry website. From there you can decide to join the Brain Health Registry or you can visit their website to learn even more.