

## M2C2-UAS Project Information Sheet – Please retain

### What is this study called and who is doing it?

This study is part of a larger project being conducted by the Mobile Monitoring of Cognitive Change (M2C2). It was developed by researchers at Pennsylvania State University (PSU) who are studying the use of mobile phones to help measure changes in thinking and memory.

The Understanding America Study (UAS) is helping this project understand the impact of taking measurements more often than is usual. We will be handling this part of the project for the PSU study team, in the UAS.

Because only certain UAS staff (Helpdesk and IT) are ever allowed to have access to your name and contact information, we will be communicating with you as usual, and collecting and safeguarding the information you provide, in the same way we do for all UAS surveys.

Researchers from both the UAS and PSU will use the de-identified data from this study to create reports and write papers.

### What is the purpose of this study? How will the data be used?

The study intends to help doctors and researchers understand the best ways to measure changes in thinking and memory.

Traditionally, people answer questions about thinking and memory once a year, maybe during a check-up with their doctor. Their answers are then compared to how they answered last year.

However, people's thinking and memory can change all the time. For example, if someone hasn't slept well or they are anxious about something or are sick, they might answer differently than they would if they were feeling better. So if they are not feeling well one year and feeling better the other, it is hard to compare one time to the other.

In this study participants will answer questions several times a day over several days. This is repeated every six months, for a total of three times in one and half years. The results will then be compared to what happens when people answer the questions once a year.

The results of doing this will help us understand what may be missed when the questions are asked only once a year. Researchers on the study team will use the data to write and publish papers and articles so that others can benefit from what we learn.

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### Why am I being invited to do this study?

You are invited to participate in the study because you are a member of the Understanding America Study online panel, you are at least 20 years old, and you have a smartphone or tablet.

A total of about 1200 UAS members will take part in the study. We are looking for people of all ages and in any kind of health to participate, across the country, to make sure everyone is fairly represented.

### What will I be doing if I join this study?

If you join the study, we will schedule you for participation in a 9-day project over a time period that works for you.

You will download an app (from the Google Play Store or the Apple App Store) that was developed by the UAS to allow people to take surveys on their phones. It is called the “Zemi” app. You will use your UAS ID and password to log in.

For eight days, the app will remind you at three random times during the day to answer a set of questions.. The questions will take about 5 minutes to fill out each time, so that is a total of 15 minutes over the whole day. On the ninth day, you will answer a 10-minute feedback survey to help us understand how the study went for you, if you had any problems, etc. Your feedback will help us make the project better. You will earn \$10 a day for doing the short surveys, and \$7 for the feedback survey, as well as our appreciation.

Then, six months from now, the UAS will contact you to do another 9-day study, exactly the same way. Then six months after that, another one. It is a total of three 9-day studies, over a year and a half.

### Is it safe to download the app onto my phone?

Yes. The app was developed by the UAS, so we can guarantee that it is private and secure, and it doesn’t harvest private information from your phone. The app can be downloaded from the Google Play store or Apple App Store. You will log in using your usual UAS login ID and password.

You will take surveys and play games using the app. The results will be stored on the UAS server, just like the responses to UAS surveys. Your privacy will always be protected.

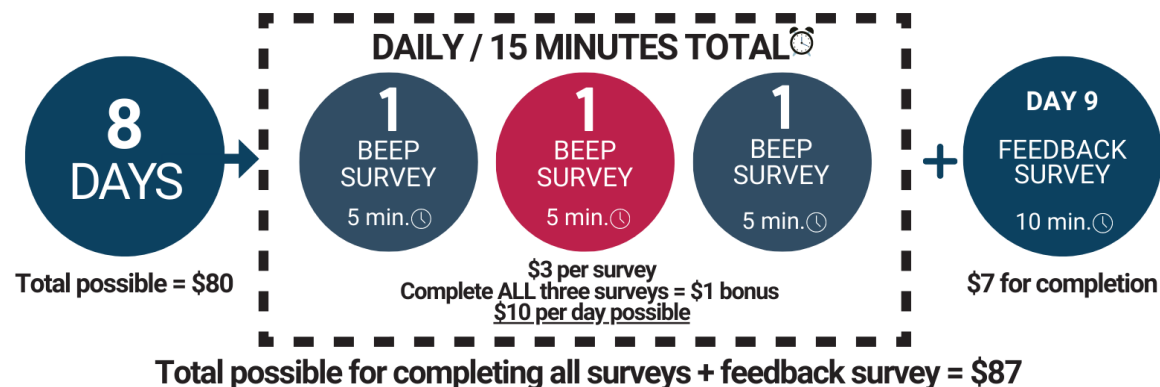
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### How much will I earn if I join?

You will earn the usual UAS rate of \$10 for each 15 minutes it takes to answer survey questions through the app, and in the feedback survey.

- On each day of the 8-day study, you will be “beeped” (prompted) by our UAS EMA app to answer 5 minutes of questions, three times a day. So that is a total of 15 minutes of questions per day.
- **You will earn \$3 each time you answer a beep and fill out questions.** If you fill out the questions all three times in a given day, you earn an additional \$1 bonus. That is a total of **\$10 each day you complete all three 5-minute surveys.**
- On the ninth day, you fill out the feedback survey. The survey will take about 10 minutes and you will earn \$7.

If you complete all 8 days of questions and the feedback survey on Day 9, it will take just over two hours total. You can earn up to a total of \$87 for the project.



We will add your earnings to your UAS account within 10 days after you finish the 9-day project. The amount you have earned for this and any other studies or surveys you have completed will be loaded onto your Clincard according to the usual UAS monthly schedule.

If you complete all three of the 9-day studies over the next year and a half, you will have spent about six and half hours total and will have earned \$261 over the course of the whole project.

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### One and a half years is a long time. What happens if I start the study and can't or don't want to finish it?

If you decide to withdraw from the study before the end, you can let us know, or simply stop using the app by deleting it or logging out. Either way, we will compensate you for any time that you completed before you withdrew or stopped.

### Will I benefit from participating?

There are no direct benefits to you from taking part in this study. Your participation in this research project may help doctors and researchers find better and more accurate ways of measuring change in thinking and memory over time.

### Is there any risk to me if I participate?

If you decide to take part in this study, the risks are the same as for any UAS survey. There is a small chance that your identity could be disclosed along with your survey answers. However, your privacy is important to us and the UAS takes every precaution to safeguard your data and your privacy. If you have questions or would like to learn more about what we do to protect you, just ask us! [uashelp@uas.edu](mailto:uashelp@uas.edu).

### How do you protect my privacy and the confidentiality of my answers?

The information you provide during the study through the phone app will be collected and protected in the same way we protect all UAS survey data.

Only the UAS Helpdesk staff who are authorized to communicate with you will know who you are, and they do not have access to your answers. Researchers at USC and at Pennsylvania State University will not have access to your name or other identifiers.

The UAS has a *Certificate of Confidentiality* from the National Institutes of Health. What this means is we are able to keep your information confidential even if we were to be subpoenaed by a court that wanted us to provide your answers to certain surveys.

There are rare circumstances in which information about you may be made available to others outside the UAS. For example, the Brany *Institutional Review Board* that oversees this research project or Federal representatives could access your records for the purpose of protecting your rights as a “human subject” in a research project. In such a case, they would not disclose your personal identifying information to anyone else.

### How will the data from this study be used, now and in the future?

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Data from this study will be used only to produce research articles (scientific and popular), manuscripts, research posters, student theses, research briefs, and presentations at research meetings.

UAS staff may combine the data from this study with data from other UAS studies that you have participated in and contributed to. This includes UAS surveys and other UAS projects such as tracking activity or measuring the environment. The combined data will be stored separately from your identity, just as we do with all UAS data.

After the study, the UAS will securely store the data to be used by this study team or other researchers who are doing similar or different kinds of research in the future. Again, the data is stored separately from your identity, so who you are is never disclosed.

If you do not wish for your data from this project to be used for these purposes, you should choose not to participate in this study.

### Do I have to participate in this study?

No! It is your choice whether or not to join this study. If you choose not to, we will continue to invite you to take UAS surveys and participate in future UAS studies. Your participation in UAS surveys is very important to us!

If you do choose to join the study, you may change your mind and leave it at any time later. Refusal to participate or stopping your participation will involve no penalty.

You can either contact the UAS helpdesk to withdraw, or simply delete or log out of the app and stop answering questions. If you decide to withdraw from the study, you will be compensated for any part of the study that you completed.

### Who do I contact about the study?

If you have questions, concerns, or complaints about the study, or if you have trouble using the UAS EMA app, or if you choose to withdraw after you have decided to participate, contact the UAS helpdesk, **by phone (855) 872-8673 or by email ([uashelp@usc.edu](mailto:uashelp@usc.edu))**.

This research has been reviewed and approved by the Brany Institutional Review Board (IRB). The IRB is a research review board that reviews and monitors research studies to protect the rights and welfare of research participants (that means you!). Contact the IRB if you have questions about your rights as a research participant or you have complaints about this research. You may contact the Brany IRB at 516-318-6877.