



DEPARTMENT OF VETERANS AFFAIRS  
RICHARD L. ROUDEBUSH VA MEDICAL CENTER  
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INDIANAPOLIS, IN 46202



**SCHOOL OF MEDICINE**  
INDIANA ALZHEIMER'S DISEASE RESEARCH CENTER

## STUDY INFORMATION SHEET

### Promoting Cultural Awareness and Diversity in Research about Alzheimer's Disease and Cognitive Health (AD-REACH)

#### ABOUT THIS RESEARCH

AD-REACH is a research project that is being conducted by both the Roudebush VA Medical Center and Indiana University School of Medicine, Indiana Alzheimer's Disease Research Center.

This form will give you information about the study to help you decide whether you want to participate. Please read this form. Should you have any questions please email [iadrc@iu.edu](mailto:iadrc@iu.edu) or call us at 317-962-9163.

#### TAKING PART IN THIS STUDY IS VOLUNTARY

You may choose not to take part in the study. You may also choose to leave the study at any time. Deciding not to participate or deciding to leave the study later will not result in any penalty or loss of benefits to which you are entitled. Your decision whether or not to participate in this study will not affect your current or future relations with Indiana University (IU) or the Richard L. Roudebush VA Medical Center (VAMC).

#### WHY IS THIS STUDY BEING DONE?

The purpose of this study is to develop a deeper understanding of how residents of the Indianapolis metro area are keeping their brain healthy and what are their opinions about Alzheimer's disease, and participation in Alzheimer's disease research.

To help us achieve this goal, we are administering a one-time survey to Veterans and non-Veteran residents of the Indianapolis metro area.

You may be eligible to take the survey if you are:

- 55 years and older
- Identify as non-Hispanic White, African-American, or Black
- And have no prior history of participating in an Alzheimer's disease research study.

The study is being conducted by Dr. Andrew J. Saykin at the Indiana Alzheimer Disease Research Center (IADRC) and Dr. Johanne Eliacin at the Richard L. Roudebush VA Medical Center. It is funded by the National Institute on Aging.

## **HOW MANY PEOPLE WILL TAKE PART?**

If you agree to participate, you will be one of 500 potential participants taking part in this study.

## **WHAT WILL HAPPEN DURING THE STUDY?**

If you agree to be in the study, you will complete a survey online at IU REDCap or over the phone. The survey may take approximately 20 minutes.

## **WHAT ARE THE RISKS OF TAKING PART IN THE STUDY?**

The risks of participating in this research are:

- Risk of being nervous or anxious while answering survey questions.
  - You can choose to not answer any question that may make you feel uncomfortable.
  - You are free to stop your participation in this study at any time without any loss to benefits or rights to which you are entitled.
- Potential loss of confidentiality.
  - Efforts will be made to keep your personal information confidential. We will not share any information about your personal identity in any presentation, writings, or papers that we publish as part of the study. All participants' information will be grouped together to protect their identity. However, we cannot guarantee absolute confidentiality. If required by law, we may have to disclose your information with organizations that oversee VA and IU research activities.

## **WHAT ARE THE POTENTIAL BENEFITS OF TAKING PART IN THE STUDY?**

We do not expect you to receive any benefit from taking part in this study. However, the information you share with us will help us provide better Alzheimer's disease education to the community and improve Alzheimer's disease research.

## **HOW WILL MY INFORMATION BE PROTECTED?**

Efforts will be made to keep your personal information confidential. We cannot guarantee absolute confidentiality. Your personal information may be disclosed if required by law. Your personal identity (such as your name, address, or other identifying information) will not be revealed in any published form, presentations, or writings about the results obtained in this study. Your identity will be held in confidence in reports in which the study may be published. **We will not ask you any questions about your health. We will also not collect any health or healthcare information about you. We will only ask for your *opinions in this survey* and your contact information.** To help protect your identity, you will be assigned a Study ID number and only that number will be used on study materials. The file that links your Study ID number to your data and your identifiable data will be kept on a secure network research server behind VA and IU firewalls. We will keep the study records as required by VA and IU research guidelines. Only personnel working on the study will have access to your information.

Because this study is a collaboration between VA and IU, all data collected during this research, including your contact information, will be saved at both VA and IU. At IU, your data will be saved in the Advanced Cyber-infrastructure facility of Indiana University. At the VA, your information will be saved on secure firewalled database servers at IU and at the VA. Research records will be maintained by the investigator in accordance with the VHA Records Control Schedule.

#### **FUTURE CONTACT:**

While participating in the survey, you will be asked if you would like to be contacted in the future by IU about other research projects. This is optional. If you choose not to be recontacted by IU in the future, you can still participate in the AD-REACH study. If you decide that you do want to be contacted again by IU, the contact information you provide will be stored with the IU Center for Neuroimaging.

Organizations that may inspect and/or copy your research records for quality assurance and data analysis include groups such as the study investigator and his/her research associates, the Indiana University Institutional Review Board or its designees, the study sponsor, the VA Research and Development Committee, and any state or federal agencies who may need to access your research records (as allowed by law). State and federal agencies may include the Office for Human Research Protections (OHRP), the National Institute of Health (NIH), the Office of Research Oversight (ORO), the VA Office of the Inspector General (OIG).

#### **WILL I BE PAID FOR PARTICIPATION?**

You will receive a \$35 Walmart gift card 2-4 weeks after completing the survey.

#### **WILL IT COST ME ANYTHING TO PARTICIPATE?**

There will be no costs to you for taking part in the study.

**VETERANS ONLY:** This research study does not include medical care or procedures. Eligibility for medical care at a VA Medical Center is based upon the usual VA eligibility policy and is not guaranteed by participation in a research study. If you receive care at the VA Medical Center, you will not be required to pay for medical care or services received as a subject in a VA research project except as follows: Some veterans are required to pay co-payments for medical care and services provided by the VA. These co-payment requirements will continue to apply to medical care and services provided by VA that are not part of this study.

#### **WHO SHOULD I CALL WITH QUESTIONS OR PROBLEMS?**

- For questions about the study, you may contact Dr. Johanne Eliacin at 317-988-5298, Dr. Andrew Saykin at 317-963-7229, or Dr. Sophia Wang at 317-963-7297, Monday through Friday, 8:00 AM - 5:00 PM.
- For questions about your rights as a research participant or to discuss problems, complaints or concerns about a research study, or to obtain information, or offer input, please contact the

IU Human Subjects Office at 317-278-3458 or 800-696-2949 or at [irb@iu.edu](mailto:irb@iu.edu) or the VA Research Personnel Office at 317-988-3032.

**CAN I WITHDRAW FROM THE STUDY?**

If you decide to participate in this study, you can change your mind and decide to leave the study at any time. If you decide to withdraw, please contact the study team to let them know that you no longer wish to participate in the study.