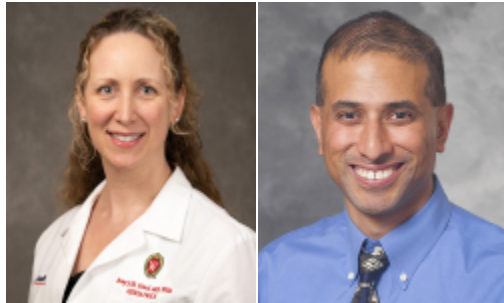


Thank you for your interest in the ADRC's new **Care Research Core**. A staff member will discuss this new opportunity with you at your next study visit.

If you have any questions, please call us at:  
**(608) 263-2582**

## The ADRC Care Research Core team



Dr. Amy Kind

Dr. Manish Shah



Dr. Andrea  
Gilmore-Bykovskyi

Dr. Brian Patterson



We have an **OPPORTUNITY** for you to participate in the Alzheimer's Disease Research Center!

Thank you for your interest in the Wisconsin Alzheimer's Disease Research Center (ADRC) **Care Research Core**. This brochure will give you more information about the new ADRC **Care Research Core** by sharing your electronic health records. Participating in this part of the **Care Research Core** will not involve any additional clinic visits or tests.



### What is Care Research?

Care Research focuses on understanding how to improve the quality of life for Alzheimer's patients and their families by looking at the care people receive (at home or within the healthcare system). One example of Care Research is to study the benefit of a nursing support program, where nurses make extra calls to check in with patients after they are released from the hospital. Researchers can compare electronic health records (EHR) of people who get this extra support to people who don't get this extra support to see if the program makes a difference. The goal of Care Research is to improve the lives of people living with Alzheimer's disease, their caregivers, and loved ones.

### What will my participation involve?

Participating in the ADRC Care Research Core involves participating in a **Care Research Core Registry** and optional **Electronic Health Records (EHR) research**.

### What is the Care Research Core Recruitment Registry?

By enrolling in the ADRC Care Research Core Recruitment Registry, you also agree to be contacted in the future about new research studies in the ADRC Care Research Core, for which you may be eligible and participate in annual phone survey visits. These visits will happen via telephone with a member of our study staff, and last between 30 and 60 minutes. The information you give us will be shared with our research team. It may also be shared with other researchers, but any information that is shared outside of our research program will not identify you directly. (Your name will not be used.)

### What is Electronic Health Records Research?

One of the ways to participate in the **Care Research Core** involves giving the ADRC permission to access your past and future electronic health records (EHR). Electronic health records include:

- Records created when you visit the hospital or clinic to keep track of your specific diagnoses, treatments and current condition (such as weight, temperature and blood pressure)
- Health insurance records, which show where, when and what type of treatment you receive. This includes services provided outside of the UW Health system.



### How will you protect the confidentiality of my electronic health records?

Only trained ADRC staff at UW-Madison will have access to your identifiable electronic health records. Stored EHR used by other researchers studying Alzheimer's disease will not contain any information that can be linked back to you. We will not share any EHR information we collect with your healthcare providers or insurance company.

### How long will you have access to my electronic health records?

The **Care Research Core** will be ongoing. When you come in for your ADRC study visits, we will ask if you would like to continue making your electronic health records available for **Care Research**. If you decide you want to end your participation, you just let us know, and we will no longer use your future electronic health records for Care Research.