

ADRC RESEARCH TIPS for Potential Study Participants: Q & A

My name is Theresa Kehne, I'm a Research Coordinator at the University of Washington, Alzheimer's Disease Research Center (UW ADRC) in Seattle. I spend a lot of time talking with patients and their care partners or family members about potential research opportunities when they come to the Memory and Brain Wellness Center for clinic visits. Here are some common questions I receive during visits:

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Q *What's the difference between the ADRC and the Memory and Brain Wellness Center?*

A The Memory and Brain Wellness Center clinic helps patients get a proper diagnosis and aids with clinical care, memory loss education, and support resources, while the Alzheimer's Disease Research Center (ADRC) does research. Getting involved in research at our ADRC is completely voluntary and won't impact a patient's medical treatment. In addition to our ADRC, there are 32 other ADRCs across the U.S., all designated by the National Institutes of Health to conduct similar research about brain health and dementia.

Q *How is research information about me protected?*

A At the UW ADRC, all researchers must comply with the federal law HIPAA (Health Insurance Portability and Accountability Act), which protects people's private health information. There is also a UW authority called the Institutional Review Board (IRB) whose job is to review all research projects at the UW and make sure that they are safe for and fair to participants. Finally, all potential participants have unlimited time to read and ask questions about a study, prior to agreeing to join the study, and then at any point during the study. This process is also known as "informed consent." Once you are enrolled in a study you can choose to withdraw at any time, without penalty.

Q *Can I see my results from a study procedure or test?*

A It is up to the investigator conducting the study to decide if any test results will be shared with participants. Examples of potential study results that may be shared are information from brain imaging (e.g., MRI or PET scans), blood draws, lumbar punctures, or written tests to assess cognitive function. Usually this matter is outlined in the informed consent documents. Every study is different and study staff can let you know which test results, if any, will be made available to you.

Q *What is a lumbar puncture?*

A A lumbar puncture is a procedure used in certain clinical and research settings during which a doctor collects a sample of cerebrospinal fluid from a person's lower back. This fluid is used clinically to help diagnose a patient. During research, cerebrospinal fluid permits direct measurement of Alzheimer's disease proteins, and may also offer investigators the opportunity to develop novel tests. To learn more about lumbar punctures and what to expect if you plan to have one, check out our "Lumbar Punctures – FAQs and Myths" page on the UW ADRC website: www.depts.washington.edu/mbwc/adrc/page/lumbar-punctures-faqs-and-myths

Q *What do Research Coordinators do?*

A Research Coordinators are responsible for the day-to-day tasks involved in a research study. Research Coordinators enroll participants, conduct study tests and lab work, maintain detailed records of research activities, work closely with investigators, and help to make sure that studies run smoothly. Research Coordinators are experts on specific research study protocols and receive extensive training in ethics, good clinical practice, and biomedical research involving human participants.

Q *What kinds of research projects/studies are going on currently that are looking for participants?*

A The UW ADRC offers research opportunities that are both observational and interventional in nature. Observational research aims to learn about brain disease and healthy aging through studying people with methods like neurologic examination, brain imaging, and cognitive tests, while interventional research evaluates the safety and effectiveness of different potential treatments and interventions (e.g., clinical trials, or investigational treatment studies). •