Many people like the idea of participating in clinical research studies but are reluctant to join a trial due to misinformation or past clinical trial history. When you join a study or trial, you may help researchers discover new ways to diagnose, treat, and prevent Alzheimer's disease and related dementias. By expanding the questions below, you can read answers to common questions about clinical trials and research studies and search for clinical trials near you.

What are clinical trials and research studies?

Clinical research is medical research that involves people. The overarching goal of clinical research is to develop knowledge that improves human health or increases the understanding of human biology. There are two types of clinical research studies: observational studies and clinical trials.

In observational studies, researchers collect information from people and compare that data over time. For example, researchers may use medical exam data, interviews or

assessments, or online survey data to learn about how different behaviors or lifestyles relate to health and disease or to understand how a disease progresses over time. Observational studies may help researchers identify new treatments or prevention strategies to test in clinical trials.

Clinical trials are a type of research that tests new drugs, medical devices, surgical procedures, or behavior and lifestyle changes such as exercise. Clinical trials may also test ways to detect and diagnose diseases and to better care for those living with diseases. Researchers determine if what is being tested, called an intervention, is safe and effective by comparing results in the test group to those in the control group.

What steps are taken to keep volunteers safe?

Researchers are required by law to ensure the safety of study participants. There is never any obligation to participate in a study and being part of a study may include risks. Risks can

include side effects of the treatment, the treatment not working, or the treatment being uncomfortable. However, the following steps help keep all volunteers safe:

- Federal law requires researchers to tell you about any known risks. You have the right to ask questions about the trial. Not all side effects of a treatment or prevention are predictable. However, researchers and Institutional Review Boards (IRB) do their best to make sure that they minimize risk, including the risk of pain, to participants.
- An IRB of doctors, scientists, and people from the general public review all studies before they begin, to make sure they are safe and necessary. Throughout the course of the study, the IRB regularly reviews each study and its results to make sure safety plans are followed.

Additionally, many clinical trials are supervised by a Data and Safety Monitoring Committee. These experts monitor study results and stop a trial early if a treatment is not working.

How do researchers decide who participates?

Researchers use a careful screening process to recruit participants. All studies have rules (inclusion and exclusion criteria such as age, other health conditions, medications, and location) that outline who can participate.

Does the research team keep my identity private?

Researchers must keep health and personal information private, as outlined by federal laws. Most studies only share results that are de-identified, or not linked to specific individuals. Some studies may share de-identified data with other qualified researchers to use in their investigations. Talk with the study coordinator to find out what information may be shared and how.

Does it cost money to join a clinical trial?

Most clinical trials do not involve any costs for the participant. Some trials offer participants a stipend, or payment, for participation. Some trials may even pay for travel, lodging, and other expenses associated with participating in the study. However, other trials may not cover these expenses, and may

require study participants to travel to the study site several times at their own expense.

If I join a study, will I get the investigational treatment?

In many studies, not all participants will receive the new treatment. Often, some participants will receive a placebo. A placebo is an inactive substance that looks like the drug or treatment being tested. Participants will not know whether they receive the new treatment or the placebo. This is done so researchers can judge whether or not the new treatment has an effect. In some cases, the researchers and study personnel are also unaware of who is in which treatment group. In a study that includes placebos, all participants receive the same standard of medical care and are important in helping to test the treatment.

If I join a trial and change my mind, can I withdraw from the study?

Participation in a clinical research study is 100% voluntary. You can quit a study at any time, for any reason, without penalty.

Why do some studies stop early?

Sometimes researchers stop studies early. However, even when the studies stop early, they can provide researchers with valuable information. Studies may be paused or stopped for a number of reasons:

- Because new information becomes available to researchers
- Due to safety concerns
- If the goals of the study are met early or by another research team
- If a treatment is found to be ineffective or to cause unexpected and serious side effects

Do participants receive information about the study results?

Researchers will collect and analyze data, and then decide what steps to take next. This may include sharing individual health information and test results with participants. Often, the collective study results are published in research journals. This is so other researchers, health care professionals, and

the public can look at them. Published results are valuable. They give other researchers information that can help their own work move forward. Before a study begins, you will receive information about:

- The study's length
- Whether you will continue to receive treatment after the study ends (if applicable)
- How you will be kept informed about study results

I can't find a study right now. How can I let researchers know I'm interested in volunteering for a clinical trial in the future?

You can make yourself available to many local and national studies by joining a registry or matching service. When you sign up for a registry, researchers can then contact you and invite you to volunteer in specific research studies. You may be invited to different types of studies, including surveys, interview studies, and medication trials.

Are there any places near me that specialize in Alzheimer's disease and related dementias research?

The Alzheimer's Disease Research Centers offer resources, support, and opportunities to participate in dementia research. The centers are located at major medical institutions across the United States and conduct clinical trials as well as observational studies of dementia and memory and aging. In addition, there may be other universities and hospitals near you that also have studies that you can join, or your doctor may be able to help you find a study.

I have some questions about participating in Alzheimer's and related dementias research studies. Who can help me?

Contact the NIA Alzheimer's and related Dementias Education and Referral (ADEAR) Center at 800-438-4380 or email for more information or help finding a clinical trial.