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Registries and Matching Services for Clinical Trials

Are you thinking of joining a clinical trial or study but can't find one that fits you? Consider joining a registry or matching service to help advance research on <u>Alzheimer's disease and dementia</u>.

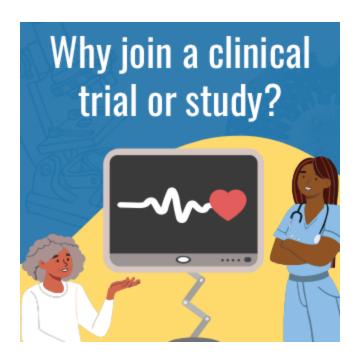
All studies have rules, called inclusion and exclusion criteria, that limit who can participate. And even studies you're eligible for might not be available in the right place or at the right time for you. However, you can make yourself available for many local and national studies by joining a registry or matching service.

Registries help speed up trials by gathering a list of "willing and able" potential participants for enrollment in clinical trials and studies. People who sign up may be referred to specific studies but are not obligated to participate. Some studies may be simple, like a survey, and can be done anywhere.

The following registries accept adult participants with a variety of backgrounds.

<u>Alzheimer's National Registry for Treatment and Diagnostics (ALZ-NET)</u>

A patient registry that collects health outcomes information on treatments for Alzheimer's from individuals being treated with an FDA-approved Alzheimer's therapy. A health care provider must enroll the participant in the database to join the registry. The information collected will help medical professionals and researchers improve and innovate care strategies for Alzheimer's and other dementias.



Read and share this infographic to learn more about how clinical research might be right for you.

Alzheimer's Prevention Registry

Open to individuals age 18 and older who are interested in learning about and possibly participating in Alzheimer's prevention clinical studies and trials.

Alzheimer's Prevention Trials (APT) Webstudy

Open to individuals age 50 and older. Take online tests once every three months to assess memory and thinking skills, gain access to scores, and be notified of opportunities for in-person assessments and clinical trials.

Asian Cohort for Alzheimer's Disease (ACAD)

Online registry for people of Chinese, Korean, and Vietnamese ancestry to understand the impact of Alzheimer's risk factors. Complete health and lifestyle questionnaires, receive cognitive testing, and provide a saliva and/or blood sample for genetic analysis.

Brain Health Registry

Open to individuals age 18 and older who want to help speed up the discovery of treatments for brain diseases and disorders by increasing the number of potential participants for clinical trials. Take online tests every six months and learn about opportunities to participate in a wide range of studies.

CADASIL Consortium

Online registry for people with or at risk for cerebral autosomal dominant arteriopathy with subcortical infarcts and leukoencephalopathy (CADASIL), a rare genetic disorder affecting the small blood vessels in the brain. After joining the CADASIL Registry, volunteers will be invited to participate in research studies on CADASIL.

CARE Registry

Online registry for Asian Americans, Native Hawaiians, and Pacific Islanders who are interested in participating in research related to Alzheimer's and related dementias, aging, caregiving, and other health topics across the lifespan.

Cleveland Clinic Healthy Brains Registry

Online registry that includes a brain health assessment with personalized recommendations. Learn about clinical trials and studies, news, and events. Brain health information resources are available in English and Spanish.

FTD Disorders Registry

A contact and research registry for people diagnosed with <u>frontotemporal disorders</u> (FTDs). It is also open to family members, caregivers, and friends of people diagnosed with an FTD.

MindCrowd

Online research study designed to analyze how brain performance changes with age. Individuals age 18 or older take a 10-minute online test and join a registry of people who may be contacted for future research studies of the aging brain.

ResearchMatch

An NIH-funded service that helps match people of all ages interested in clinical trials with researchers. Available in English, Spanish, and Chinese.

Registry for Older African Americans at-Risk for Alzheimer's Disease (ROAAR-AD)

A registry for African Americans, age 60 and older, to improve the development of Alzheimer's diagnostics and treatments tailored for African Americans. Join the registry to receive a medical evaluation, take cognitive tests, provide a blood sample, and undergo MRI brain imaging to evaluate factors that increase the risk for developing Alzheimer's. Based on this information, individuals may be contacted for future research studies on the aging brain and Alzheimer's in African Americans.

TrialMatch

The Alzheimer's Association's clinical studies matching service for individuals with Alzheimer's, caregivers, and healthy volunteers.

Trial-Ready Cohort - Down Syndrome

An NIH-funded registry to enroll healthy people with Down syndrome, between the ages of 25 and 55, to participate

in future Alzheimer's prevention studies. Participants will undergo cognitive and clinical assessments, brain imaging, and genetic and biomarker testing. They will also receive referrals for other studies.



For more help finding opportunities to participate in research, contact the NIA ADEAR Center via <u>email</u> or phone at **800-438-4380**.

You may also be interested in

- Learning more about <u>participating in Alzheimer's disease research</u>
- Reading about <u>clinical trials and studies</u>
- Finding out about benefits, risks, and safety of clinical research

This content is provided by the NIH National Institute on Aging (NIA). NIA scientists and other experts review this content to ensure it is accurate and up to date.

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