

RECRUITMENT ACCELERATOR
FOR DIVERSITY IN AGING RESEARCH
COGNITIVE LOSS AND DEMENTIA (RADAR-CLD)

Community Research Liaison (CRL) Training Resources



RECRUITMENT PARTNERS LLC
IN COLLABORATION WITH
MOUNT SINAI HOSPITAL
SUNY UPSTATE MEDICAL UNIVERSITY



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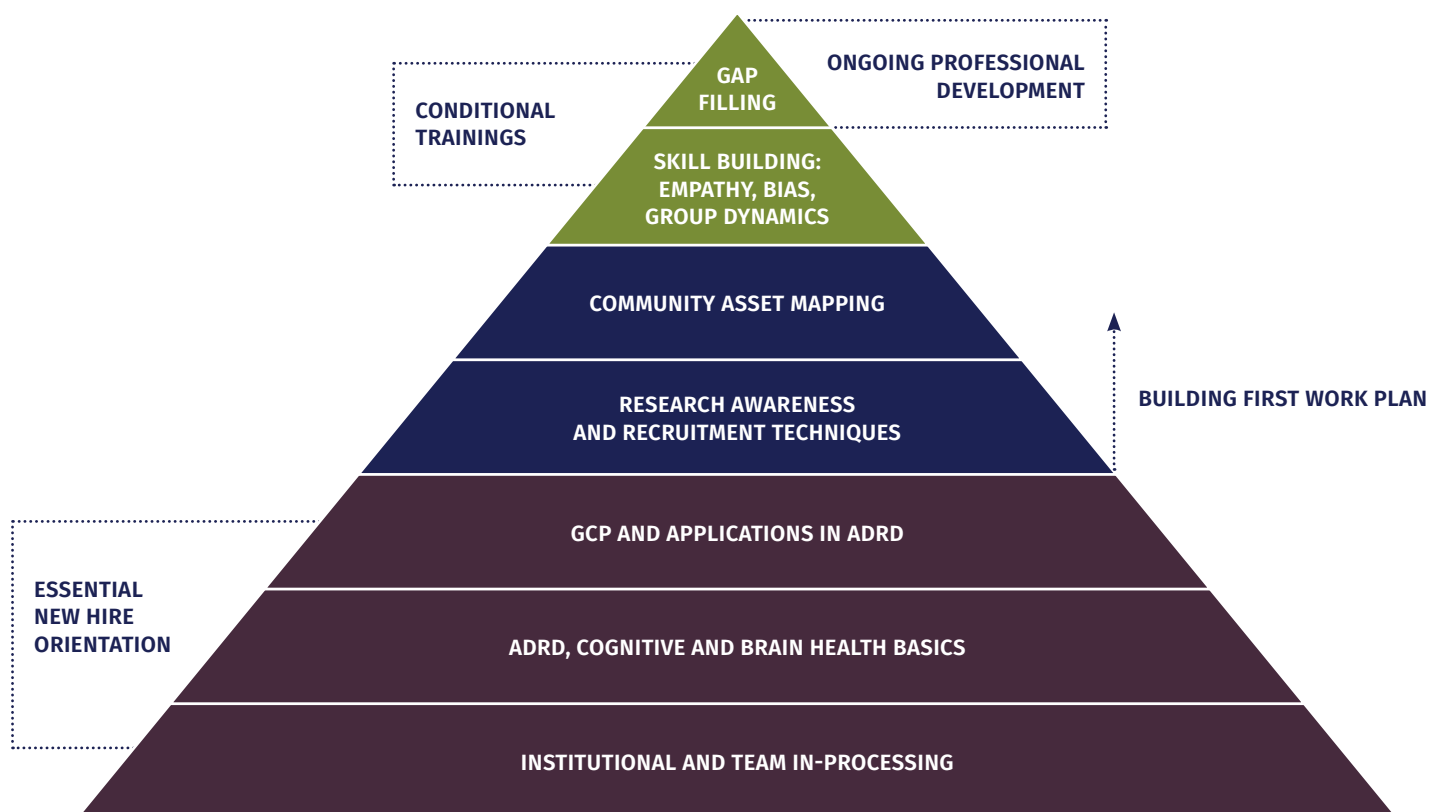
This project is funded by
National Institute on Aging
grant number R24AG065163



A Note on Pace



Orientation and training schema recommendations are summarized in the below graphic. Time to completion is an educated guess based on the job description posted. Some tailoring may be needed.



Institutional and Team In-processing



Each academic institution will have their own internal procedures for new hire in-processing, orientation, and team introductions which is expected to take 3-10 days. Respective hiring managers are accountable for following those institutional procedures. Each institution should include familiarization with the RADAR-CLD grant in their in-processing.

THIS WOULD INCLUDE REVIEW OF:

- RADAR-CLD application (project aims, scope, CRL role, and timeline)
- Stakeholders who have pledged support
- Grant website <https://www.radar-cld.com/>

WHEN THE CRL HAS COMPLETED THIS TRAINING, THEY WILL BE ABLE TO:



Describe the RADAR-CLD project scope

Alzheimer's Disease, Cognitive Aging, and Brain Health Basics



THESE RESOURCES WILL PROVIDE THE CRL WITH BASIC KNOWLEDGE...

WHEN THE CRL HAS COMPLETED THIS TRAINING, THEY WILL BE ABLE TO:

- ✓ Describe the difference between normal cognitive aging and AD and dementia.
- ✓ List at least five actions that promote brain health over the life course.
- ✓ Summarize at least three standard cognitive tests and their delivery.

SELF-PACED RESOURCES INCLUDE:

Dementia as a Disease and Diagnosis

- If CRL does not have ADRD background -
<https://www.nia.nih.gov/alzheimers/alzheimers-scientific-images-and-video>
- Alzheimer's Disease and Related Dementias by the HRSA Health Workforce -
<https://bhw.hrsa.gov/grants/geriatrics/alzheimers-curriculum>
 - Designed for primary care workforce about dementia
 - Topics include understanding and discussing diagnosis, treatment options, roles of various providers. A supplemental section for caregivers may also be helpful to understand the caregiver perspective.
- Cognitive Assessment Tutorials
 - Introduction to Cognitive Screening Administration and Scoring
 - <https://actonalz.org/video-tutorials>
- Brain health
 - <https://www.youtube.com/watch?v=OV2TspM8PDg>
 - <https://stayingsharp.aarp.org/about/brain-health/what-is-staying-sharp/>
 - <https://acl.gov/brain-health>

Good Clinical Practice and its Application in AD, and Cognitive Health Research Basics

FOUNDATIONAL MATERIAL WITH ADDITIONAL BENEFIT OF ESTABLISHING COMMON VOCABULARY

WHEN THE CRL HAS COMPLETED THIS TRAINING, THEY WILL BE ABLE TO:



Review major causes of disparities in AD research and describe better practices that address them.

Research Fundamentals

Fundamental/introductory materials in lay language about research to be read/watched independently then discussed with supervisor:

- <https://www.aarp.org/health/conditions-treatments/info-2020/open-clinical-trials.html>
- <https://www.aarp.org/health/drugs-supplements/info-2020/participating-in-clinical-trials.html>
- <https://www.youtube.com/watch?v=RGK3VKkyVxs>
- <https://www.hhs.gov/ohrp/education-and-outreach/about-research-participation/informational-videos/index.html>
- https://www.ted.com/talks/luz_claudio_why_science_needs_community_engagement

Introduction to Terminology and Concepts in AD Clinical Research

- **INTEGRATIVE SEMINARS**

Zoom recordings with Drs. Sano and Brangman as they review three key points from the GCP training and review how they play out in live research situations. Points covered will be Informed Consent, Confidentiality, and Recruitment and Retention.

- **SELF-PACED: CITI GOOD CLINICAL PRACTICE (GCP) COURSES -**

<https://about.citiprogram.org/en/courses/>

These courses are designed to prepare research staff in the conduct of clinical trials with human participants. The 12 modules included in the course are based on ICH GCP Principles and the Code of Federal Regulations (CFR) for clinical research trials in the U.S. The course is self-paced and takes approximately six hours to complete and generates a credential. Each institution has its own license and requirements to be met. At a minimum, CRL should complete GCP and Basic Biomedical Course by CITI.



Racial Disparities in Research: Background and Action

BACKGROUND READING

- Alzheimer's Association Facts and Figures 2021 Special Report: Race Ethnicity and Alzheimer's in America
<https://www.alz.org/media/documents/alzheimers-facts-and-figures.pdf>
- <https://www.usagainstalzheimers.org/learn/disparities>

BACKGROUND VIEWING

- Ask the Expert with Dr. Brangman: Health Disparities and Dementia
https://www.facebook.com/watch/live/?v=268339524438999&ref=watch_permalink



PRACTICAL APPLICATION: Review local or institutional studies and pick two studies to analyze how they may or may not address disparities and discuss with supervisor or at a team meeting.

Research Recruitment, Awareness Building and Recruitment Techniques



The training now starts to shift into more background and tool review that can be applied to developing the CRL's first work plan. Each team may have a format and supervisor accountability process for work plans.

WHEN THE CRL HAS COMPLETED THIS TRAINING, THEY WILL BE ABLE TO:

- ✓ Describe common recruitment techniques.
- ✓ Describe the basic scope of the RADAR accelerator.

Recruiting

- Self-paced Review subject motivation videos at Clinical Trials Participant Videos
<https://www.nia.nih.gov/alzheimers/alzheimers-scientific-images-and-video>
- Review NIA Recruiting Older Adults into Research (ROAR) Toolkit -
<https://www.nia.nih.gov/health/recruiting-older-adults-research-roar-toolkit>

This kit has easy-to-use, customizable materials that feature information on:

- Why research is important to healthy aging
 - What volunteers need to know about research studies
 - How older adults can make a difference by participating
 - Easy steps to take
- Review items in the NIA ADORE repository
(<https://www.nia.nih.gov/research/alzheimers-dementia-outreach-recruitment-engagement-resources>) that focus on recruitment and research awareness raising in diverse communities such as:
 - <https://www.youtube.com/watch?v=gg06SY-zuVg&t=8s>
 - <https://www.youtube.com/channel/UCAFdURPZNVdWZvNahpqKsDQ/videos>

The Global Alzheimer's Platform Foundation (GAP) is a nonprofit organization that offers a network of over 80

clinical trial sites that share knowledge and experience toward research progress. Their YouTube channel offers several recruitment videos, including content that focuses on recruiting African Americans and a clinical trials awareness video.

- <https://care.nursing.wisc.edu/dementia-friendly-toolkit/>

- Review of RADAR accelerator model
 - Review RADAR-CLD grant application as needed
 - Review Accelerator Manual

Community Asset Mapping



Asset Mapping is a tool that relies on a core belief of asset-based community development; namely, that good things exist in communities and that those things can be highlighted and encouraged — these are assets suited to advancing those communities.

- Introduction to Asset Mapping
https://youtu.be/_muFMCLebZ4
- Duncan, Dan. “Asset Mapping Toolkit”
<https://clearimpact.com/wp-content/uploads/2016/02/Asset-Mapping-ToolkitRLG.pdf>

Skill Building (Optional Ongoing Training)



- **EMPATHY**

Empathy is a mindset and behavior that helps us identify key social challenges and develop useful, effective, culturally appropriate solutions for them. Every single person is an expert in their own experience, and empathy allows us to better understand that experience from their perspective, so we can better work with and support them.

See <https://csis.upenn.edu/independent-learning/empathy-map/> as an example online training or <https://www.onlinelearning.upenn.edu/covid-19-compassion-our-courses-during-uncertain-times>

- **UNCONSCIOUS BIAS**

Unconscious biases are social stereotypes about certain groups of people that individuals form outside their own conscious awareness. Everyone holds them.

- <https://naaee.org/sites/default/files/assetmappingworkbook2013.pdf>

See also McKnight <https://resources.depaul.edu/abcd-institute/resources/Pages/tool-kit.aspx>



ADDITIONAL SKILL BUILDING AREAS TO EXPLORE:

- Emotional Intelligence
- Community Engagement Skills
- Group dynamics and leading successful discussions

CRL Training Evaluation



When training is complete, the CRL should be able to discuss the main objectives set forth in the manual with their manager or team member overseeing the CRL training and complete the Alzheimer's Disease Knowledge Scale.

THE CRL SHOULD BE ABLE TO:

- ✓ Describe the institution's program/project scope.
- ✓ Describe the difference between normal cognitive aging, AD, and dementia.
- ✓ List at least five actions that promote brain health over the life course.
- ✓ Summarize at least three standard cognitive tests and their delivery.
- ✓ Review major causes of disparities in AD research and describe better practices that address them.
- ✓ Describe common recruitment techniques.
- ✓ Describe the basic scope of an accelerator.
- ✓ Describe barriers and strengths of recruitment at your organization and how to plan for and around them.
- ✓ Correctly answer questions of the Alzheimer's Disease Knowledge Scale

Alzheimer's Disease Knowledge Scale

Question Number & Item		True or False	
1.	People with Alzheimer's disease are particularly prone to depression.	T	F
2.	It has been scientifically proven that mental exercise can prevent a person from getting Alzheimer's disease.	T	F
3.	After symptoms of Alzheimer's disease appear, the average life expectancy is 6 to 12 years.	T	F
4.	When a person with Alzheimer's disease becomes agitated, a medical examination might reveal other health problems that caused the agitation.	T	F
5.	People with Alzheimer's disease do best with simple, instructions giving one step at a time.	T	F
6.	When people with Alzheimer's disease begin to have difficulty taking care of themselves, caregivers should take over right away.	T	F
7.	If a person with Alzheimer's disease becomes alert and agitated at night, a good strategy is to try to make sure that the person gets plenty of physical activity during the day.	T	F
8.	In rare cases, people have recovered from Alzheimer's disease.	T	F
9.	People whose Alzheimer's disease is not yet severe can benefit from psychotherapy for depression and anxiety.	T	F
10.	If trouble with memory and confused thinking appears suddenly, it is likely due to Alzheimer's disease.	T	F
11.	Most people with Alzheimer's disease live in nursing homes.	T	F
12.	Poor nutrition can make the symptoms of Alzheimer's disease worse.	T	F
13.	People in their 30s can have Alzheimer's disease.	T	F
14.	A person with Alzheimer's disease becomes increasingly likely to fall down as the disease gets worse.	T	F
15.	When people with Alzheimer's disease repeat the same question or story several times, it is helpful to remind them that they are repeating themselves.	T	F
16.	Once people have Alzheimer's disease, they are no longer capable of making informed decisions about their own care.	T	F
17.	Eventually, a person with Alzheimer's disease will need 24 hour supervision.	T	F
18.	Having high cholesterol may increase a person's risk of developing Alzheimer's disease.	T	F
19.	Tremor or shaking of the hands or arms is a common symptom in people with Alzheimer's disease.	T	F
20.	Symptoms of severe depression can be mistaken for symptoms of Alzheimer's disease.	T	F
21.	Alzheimer's disease is one type of dementia.	T	F
22.	Trouble handling money or paying bills is a common early symptom of Alzheimer's disease.	T	F
23.	One symptom that can occur with Alzheimer's disease is believing that other people are stealing one's things.	T	F
24.	When a person has Alzheimer's disease, using reminder notes is a crutch that can contribute to decline.	T	F
25.	Prescription drugs that prevent Alzheimer's disease are available.	T	F
26.	Having high blood pressure may increase a person's risk of developing Alzheimer's disease.	T	F
27.	Genes can only partially account for the development of Alzheimer's disease.	T	F
28.	It is safe for people with Alzheimer's disease to drive, as long as they have a companion in the car at all times.	T	F
29.	Alzheimer's disease cannot be cured.	T	F
30.	Most people with Alzheimer's disease remember recent events better than things that happened in the past.	T	F

Alzheimer's Disease Knowledge Scale - **ANSWER KEY**

Question Number & Item		True or False
1.	People with Alzheimer's disease are particularly prone to depression.	True
2.	It has been scientifically proven that mental exercise can prevent a person from getting Alzheimer's disease.	False
3.	After symptoms of Alzheimer's disease appear, the average life expectancy is 6 to 12 years.	True
4.	When a person with Alzheimer's disease becomes agitated, a medical examination might reveal other health problems that caused the agitation.	True
5.	People with Alzheimer's disease do best with simple, instructions giving one step at a time.	True
6.	When people with Alzheimer's disease begin to have difficulty taking care of themselves, caregivers should take over right away.	False
7.	If a person with Alzheimer's disease becomes alert and agitated at night, a good strategy is to try to make sure that the person gets plenty of physical activity during the day.	True
8.	In rare cases, people have recovered from Alzheimer's disease.	False
9.	People whose Alzheimer's disease is not yet severe can benefit from psychotherapy for depression and anxiety.	True
10.	If trouble with memory and confused thinking appears suddenly, it is likely due to Alzheimer's disease.	False
11.	Most people with Alzheimer's disease live in nursing homes.	False
12.	Poor nutrition can make the symptoms of Alzheimer's disease worse.	True
13.	People in their 30s can have Alzheimer's disease.	True
14.	A person with Alzheimer's disease becomes increasingly likely to fall down as the disease gets worse.	True
15.	When people with Alzheimer's disease repeat the same question or story several times, it is helpful to remind them that they are repeating themselves.	False
16.	Once people have Alzheimer's disease, they are no longer capable of making informed decisions about their own care.	False
17.	Eventually, a person with Alzheimer's disease will need 24 hour supervision.	True
18.	Having high cholesterol may increase a person's risk of developing Alzheimer's disease.	True
19.	Tremor or shaking of the hands or arms is a common symptom in people with Alzheimer's disease.	False
20.	Symptoms of severe depression can be mistaken for symptoms of Alzheimer's disease.	True
21.	Alzheimer's disease is one type of dementia.	True
22.	Trouble handling money or paying bills is a common early symptom of Alzheimer's disease.	True
23.	One symptom that can occur with Alzheimer's disease is believing that other people are stealing one's things.	True
24.	When a person has Alzheimer's disease, using reminder notes is a crutch that can contribute to decline.	False
25.	Prescription drugs that prevent Alzheimer's disease are available.	False
26.	Having high blood pressure may increase a person's risk of developing Alzheimer's disease.	True
27.	Genes can only partially account for the development of Alzheimer's disease.	True
28.	It is safe for people with Alzheimer's disease to drive, as long as they have a companion in the car at all times.	False
29.	Alzheimer's disease cannot be cured.	True
30.	Most people with Alzheimer's disease remember recent events better than things that happened in the past.	False

Glossary of Terms



A

Accelerator

A group of stakeholders, consisting of community members and organizations, research participants, researchers, and health care providers, which review and improve recruitment for selected studies. The group will recommend ways in which the selected studies can be improved to attract more people from diverse backgrounds. The groups will also explore new activities that educate and connect the community to available research opportunities.

Activities of Daily Living (ADLs)

Activities of daily living (ADLs) refer to the basic tasks an individual does on a day-to-day basis that are fundamental in caring for oneself. An individual's ability to perform ADLs is used as a measure of an individual's functional status, especially that of older adults or those with disabilities. ADLs include are eating, bathing/hygiene, dressing, mobility, and toileting. ADLs should not be confused with Instrumental activities of daily living (IADL) which include more advanced skills such as managing finances, using transportation, cooking, performing household chores, and shopping.

Alzheimer's disease (AD)

Alzheimer's disease (AD) is the most common cause of dementia, accounting for most cases of dementia and is the result of buildup of protein deposits (amyloid plaques and tau) in the brain. AD progresses in severity from the mildest stage, often called MCI or mild cognitive impairment, to the most severe stage, where a person requires assistance to complete the basic activities of daily living.

Amyloid beta (A β or Abeta)

Amyloid beta is a normal protein found in the human brain, but they build up into plaques in the brains of people developing Alzheimer's disease (AD) and disrupt cell-to-cell signaling and may cause inflammation in the brain.

Amyloid beta starts to accumulate in the brain decades before symptoms of AD present. Many new drug compounds focus on removal or prevention of amyloid beta buildup to potentially to reduce or delay the onset of dementia.

Aphasia

A loss of the ability to produce and/or understand language.

APOE

Apolipoprotein E, commonly referred to as APOE, is a protein found in the amyloid plaques in Alzheimer's disease. It comes in several types or "alleles" -2, 3, and 4. Each person has two alleles (one from each parent) which you can have in any combination of the three types. APOE-4 has been shown to increase the risk of AD but does not cause AD, whereas APOE-2 decreases the risk of Alzheimer's disease. APOE-3, the allele that occurs most commonly, neither increases nor decreases the risk of Alzheimer's disease. A genetic test can determine an individual's APOE status.

Apraxia

The loss of the ability to perform tasks that require remembering patterns or sequences of movements (like giving a salute).

Assent

Demonstrating an agreement to participation by actively and willingly taking part. People with certain disorders, including dementia, may be legally unable to consent to research participation, but they must assent to participate.

Atrophy

A reduction in size after normal, mature growth. In brain tissue specifically, a loss of neurons and the connections between them. Various symptoms arise due to the area of the brain that has atrophied.

B

Biomarker

Biomarkers are measures of a substance in the body, shown by the results of laboratory and imaging tests, which can indicate a disorder, infection, or environmental exposure. For example, elevated PSA levels may indicate prostate cancer and elevated blood pressure readings may indicate high blood pressure. In Alzheimer's disease research, biomarkers are markers in the blood or spinal fluid, levels of amyloid or tau pathology in the brain, or patterns of brain activity on functional MRI scan.

Find out more in the NIA publication [Biomarkers for Dementia Detection and Research](#)

Blinded Studies

Single-blind studies are studies in which the participants do not know which treatment they are receiving. This is beneficial because the patients can describe what happens without bias.

Double-blind studies are studies in which neither the research participants nor the study staff know which participants are receiving which treatment. Double-blind trials are believed to produce unbiased results because the expectations of researchers and participants about the treatments' effectiveness do not affect the outcome of the trials.

C

Clinical trial

A research study that is designed to answer specific questions about the safety and effectiveness of new therapies or new ways of using known treatments.

TYPES OF CLINICAL TRIALS:

- **Diagnostic trials** determine better tests or procedures

for diagnosing a particular disease or condition.

- **Natural history studies** provide valuable information about how disease and health progress.
- **Prevention trials** look for better ways to prevent a disease in people who have never had the disease or to prevent the disease from returning.
- **Quality of life trials** (or supportive care trials) explore and measure ways to improve the comfort and quality of life of people with a chronic illness.
- **Screening trials** test the best way to detect certain diseases or health conditions.
- **Treatment trials** test new treatments, new combinations of drugs, or innovative approaches to treatment.

Clinical trials are conducted in "phases." The trials at each phase have a different purpose and help researchers answer different questions.

- **Pre-clinical trial** – Non-human trials to determine a safe starting dose for use in human study.
- **Phase I trials** — An experimental drug or treatment in a small group of people (20–80) for the first time. The purpose is to evaluate its safety and identify side effects.
- **Phase II trials** — The experimental drug or treatment is given to a larger group of people (100–300) to determine its effectiveness and to further evaluate its safety.
- **Phase III trials** — The experimental drug or treatment is given to large groups of people (1,000–3,000) to confirm its effectiveness, monitor side effects, compare it with standard or equivalent treatments.
- **Phase IV trials** — After a drug is licensed and approved by the FDA, researchers track its safety, seeking more information about its risks, benefits, and if there are other conditions that it may treat.

Community Advisory Board (CAB)

A panel that is made up of representatives of diverse layers of community. Its purpose is to provide a public forum for community members to present and discuss their needs and concerns related to a project.

Community-based participatory research (CBPR)

A partnership approach to research that equitably involves, for example, community members, organizational representatives, and researchers in all aspects of the research process and in which all partners contribute expertise and share decision making and ownership.

Community Research Liaison (CRL)

A novel research professional who is uniquely focused on building an environment of trust and mutual respect among community members. The CRL will maximize research participation by connecting the community and research partners through Accelerator activities.

Consensus diagnosis

A process in which psychiatrists, neurologists, neuropsychologists, expert memory testers, clinical nurses, and research social workers discuss the findings from a research appointment and assign a research participant a diagnosis.

Co-Investigator (CO-I)

An individual working in collaboration with the Program Director/Principal Investigator in the scientific development or execution of a project.

Control

A healthy person with no memory complaints.

D

De-identified data

Data that are labeled with a study code and contain no personal or identifying information which could link a particular research participant to a specific group of data.

Dementia

An umbrella term used to describe any type of memory or cognitive impairment that progresses over time and interferes with daily functioning and abilities.

Durable Power of Attorney

A document that names a person to handle all of another person's affairs if that person becomes incapacitated.

E

Eligibility Requirements or Inclusion/Exclusion Criteria

The criteria determining whether a person may or may not be allowed to enter a study. These criteria may include age, gender, the type and stage of a disease, previous treatment history, other medical conditions, language spoken, access to internet, and assistance of a study partner.

F

Familial Alzheimer's disease

An uncommon form of Alzheimer's disease (3% of cases) that usually onsets earlier in life (defined as before the age of 65, usually between 50 and 65 years of age) and is caused by a genetic mutation.

Frontotemporal dementia (FTD)

Least common form of dementia. Caused by the death of nerve cells in the frontal and/or temporal lobes of the brain. Symptoms include changes in personality and behavior as well as difficulty controlling emotions.

G

Gene

A gene is a specific subunit of DNA that codes for a specific protein.

Genetic Test

A genetic test allows the identification certain genes that may increase the risk of Alzheimer's disease. Testing for the APOE gene is common in some AD research.

H

Healthy volunteer

A person with no known significant health problems who participates in clinical research to test a new drug, device, or intervention. Sometimes referred to as a control.

Human Subject

A living individual about whom a researcher obtains data through intervention or interaction with the individual. Outside of protocol development and technical reporting, this term should not be used when referring to a research participant.

In vitro studies

Studies which are conducted outside the living organism.

In vivo studies

Studies which are conducted inside the living organism.

Inclusion/exclusion criteria

See [Eligibility Requirements](#)

Informed Consent (IC)

The process of educating and legally protecting people who participate in research before choosing to participate. Study participants receive documents known as consent forms to review; these forms describe the procedures, tests, data collection, and privacy protection of the study. These forms may be provided digitally or in print and must be signed prior to participation in the research.

Informed consent is also meant to ensure participant safety and to prevent unethical research on vulnerable populations. Researchers are responsible for evaluating each participant's ability to understand the research process, and if participants are unable to provide informed consent because of problems with memory or confusion, authorized legal representatives may be able to give permission in their place.

Institutional review board (IRB)

A committee that ensures that a clinical trial is ethical and that the rights of study participants are protected. IRBs may be associated with an academic institution or may be a third-party commercial IRB. Both types of IRBs must comply with the same federal guidelines. All clinical trials in the United States must be approved by an IRB before they begin.

L

Legally authorized representative

A person who is legally able to make decisions on behalf of someone else. This capacity is commonly given in a Durable Power of Attorney form.

Lewy bodies

Lewy bodies are small buildups of protein in some brain cells, which are only visible through a microscope. Lewy bodies are associated with dementia with Lewy bodies and Parkinson's disease dementia.

Lumbar puncture

A medical procedure where a small amount of cerebrospinal fluid (CSF) is taken from a person's lower back. CSF can be analyzed for amyloid, indicating whether a person has Alzheimer's disease.

M

Mild cognitive impairment (MCI)

A stage between the expected cognitive decline of aging and the more serious decline of dementia. This can involve, but is not limited to, memory and language problems. Although typically associated with dementia, mild cognitive impairment (MCI) can also be caused by other conditions such as anxiety, depression, and drug interactions.

Mini Mental State Examination (MMSE)

A brief 30-point cognitive test widely used for detecting cognitive impairment and can be a useful screening tool for several neurological diseases, including various forms of dementia. **A general guide to MMSE scoring:**

- **25-30 points:** normal cognition
- **21-24 points:** mild dementia
- **10-20 points:** moderate dementia
- **9 points or lower:** severe dementia

Mixed dementia

Where more than one type of dementia is present in a patient.

Montreal Cognitive Assessment (MoCA)

A brief 30-point cognitive test widely used for detecting cognitive impairment and can be a useful screening tool for several neurological diseases, including various forms of dementia. **A general guide to MOCA scoring:**

- **>26 points:** normal cognition
- **≤25 points:** indication of some form of cognitive impairment

MRI

Magnetic Resonance Imaging (MRI) is a non-invasive imaging technology that produces three dimensional detailed anatomical images without the use of radiation. It is often used for disease detection, diagnosis, and treatment monitoring.

O

Off-Label

Use/prescription of a drug for a condition other than that for which it has been officially approved.

P

Parkinson's Disease

A long-term degenerative disorder of the central nervous system that mainly affects the motor system, characterized by tremor, decreased bodily movement, rigidity, and instability.

Peer Review

The process by which proposed research is reviewed by independent researchers to evaluate the importance of the research.

PET Imaging

Positron Emission Tomography (PET) imaging is a brain scanning technology that reveals the presence of amyloid proteins in the brains of living people. It aids in the accurate diagnosis of Alzheimer's disease, which previously could be diagnosed with accuracy only after a patient's death.

PET is also being used in a newer application which can show the spread and deposition of tau proteins in the brain of living individuals.

Pick's disease

The original name for the condition now known as behavioral variant frontotemporal dementia (bvFTD).

Pilot Project

A small-scale preliminary study designed to evaluate usefulness, length, cost, and potential adverse effects of a study before a full-scale research project takes place.

Placebo

An inactive substance that looks identical to an active experimental medication but has no pharmacological effect. Comparing the results from participants taking experimental medications and participants taking placebos may indicate whether changes in the experimental medication group are a result of the treatment.

Principal Investigator

A Principal Investigator is the head researcher, often with PhD credentials, who leads the clinical research team and, along with the other members of the research team, regularly monitors study participants' health to determine the study's safety and effectiveness.

Progressive supranuclear palsy (PSP)

An uncommon brain disorder that affects movement, control of walking (gait) and balance, speech, swallowing, vision, mood, and behavior, and thinking. The disease results from damage to nerve cells in the brain.

Protocol

A Protocol is a carefully designed research plan to safeguard the participants' health and answer specific research questions. The protocol will include information on the purpose(s), design, methodology, statistical criteria, and structure of the trial. A protocol is required for a study obtain ethical approval from a Research Ethics Committee or Institutional Review Board (IRB).

R

Randomly assigned (randomization)

A method based on chance by which study participants are assigned to research groups, for example, to groups that receive experimental medications and groups that receive a placebo (an inactive substance that looks identical to an active experimental medication but has no pharmacological effect). By equally distributing people with particular characteristics among all the trial groups, randomization controls for differences that researchers are not interested in studying.

Repository

A facility where a collection of biological samples (like blood or CSF) is stored, or an online collection of information.

Repurposing drugs

The discovery of new uses for clinically approved drugs.

Research registry

A large collection of people who are interested in participating in research studies. A registry maintains updated information on participants and informs participants when they may be eligible for particular research studies. Registries are sometimes referred to as a “research ready cohort”.

S

Stakeholder

Persons or groups that have a vested interest in the research. Examples of stakeholders include but are not limited to: community members, research participants, care partners, medical professionals, community organizers, and researchers.

Study partner / Study buddy

A friend, relative, or other associate of a study participant who knows the research participant well and is able to answer potentially sensitive questions about the participant’s daily functioning and behavior can provide support to the study participant for the duration of the research. Study partners are often responsible for accompanying the participant to study appointments, reporting changes in the participant,

and providing other observations as required by the study protocol. For most people, this is a spouse or an adult child, but the study partner can also be a close friend or a neighbor.

See more at [How Study Partners are Vital to Alzheimer’s Research | National Institutes of Health \(NIH\)](#)

Study sponsor

An organization that provides funding for a study and monitors the funded studies to ensure compliance with the research protocol. Study sponsors are commonly government agencies, not-for-profit science organizations, and pharmaceutical companies.

T

Tau

A protein in the body that aids in stabilizing proteins that support the structure and shape of neurons. Tau are abundant in neurons in the central nervous system, however misfolded tau can no longer stabilize proteins and may cause harm to brain cells. Some research shows that the pattern of tau correlates to brain atrophy and cognitive decline. For example, research shows that patients with word-finding difficulties tend to have more tau in the left hemisphere of the cortex, which processes language.

V

Vascular dementia

Second most common form of dementia. Caused by damaged blood vessels in the brain. Symptoms vary but may include memory loss and language difficulties.

Voluntary

Participating out one’s own free will, without compulsion or obligation, and having the power to end participation whenever someone chooses.

RESOURCES FOR TERMS:

[Glossary of Common Terms | National Institutes of Health \(NIH\)](#)

[Glossary | Alzheimer's Association](#)