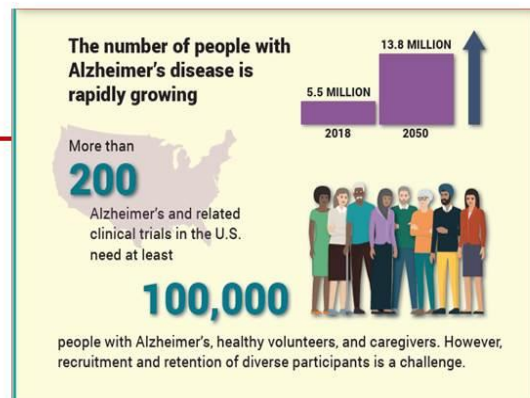

Together We Make the Difference
National Strategy for Recruitment and Participation
in Alzheimer's & Related Dementias
Clinical Research

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Urgent mission

- National Alzheimer's Plan goal 1: "To effectively treat or prevent Alzheimer's by 2025"
- Public funding is increasing, research is accelerating
- Drugs and other interventions in rapid development, moving to clinical trials to be tested
- 200+ trials currently underway, seeking 100,000+ participants



But, more studies competing for volunteers

- Many research sites are slow to meet volunteer recruitment targets, while others do not reach their targets at all
 - Delays in time to complete studies
 - Increases research costs
- Precision medicine – right treatment, right person, right time – means representation of all is critical



Recruitment challenges for AD/ADRD studies

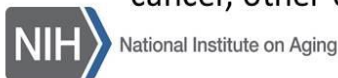
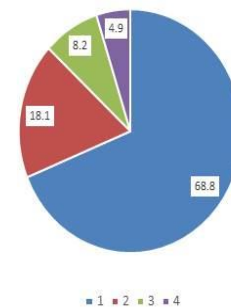
- Participant burden:
 - Study partner requirements
 - Invasive and time-consuming procedures
- Strict eligibility criteria
- Lack of capacity, awareness, and resources among primary care physicians
- Need for cognitively unimpaired volunteers



NIA analysis of inclusion in AD/ADRD trials

- Older adults *are* included
- Representation of non-white populations is variable
- Trial exclusion criteria may negatively impact participation of underrepresented groups:
 - Multiple medications
 - Neurological, cardiovascular, diabetes, cancer, other co-morbidities

% by Race of participants in NIH-funded AD trial publications



Overcoming challenges, opening doors

What is NIA doing in collaboration with others to overcome inclusion and recruitment challenges?

- Developing national recruitment strategy
- Funding opportunities and infrastructure
- Outreach and education

Will require a wide variety of stakeholders:

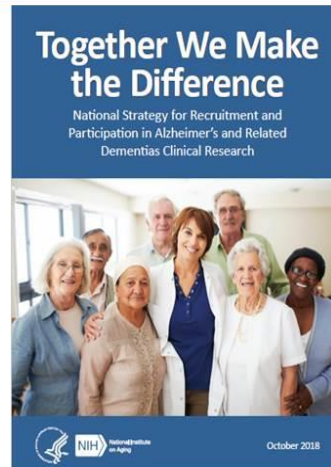
industry, clinicians, public, researchers, advocates



National Strategy for Recruitment and Participation in Alzheimer's & Related Dementias Research

GOAL:

- Engage broad segments of the public in Alzheimer's and related dementias research
- Focus on underrepresented communities
- Assist studies in successfully and more quickly enrolling and retaining people in studies to better understand and eventually cure these disorders.



<https://www.nia.nih.gov/research/recruitment-strategy>



4 areas of focus

- Increase awareness and engagement
- Build and improve infrastructure
- Engage local communities and support participants
- Develop an applied science of recruitment



1. Increase Awareness and Engagement

Strategic Priorities:

- Identify diverse audiences needing tailored messages and best locations and modes of outreach at the national and community levels.
- Develop and disseminate culturally and linguistically appropriate content for outreach and awareness.



2. Build and Improve Infrastructure

Strategic Priorities:

- Leverage and improve existing registry infrastructure.
- Develop and adapt information technologies to support recruitment.
- Structure staffing and organizational incentives to support and reward successful recruitment.
- Support study site capacity building.
- Improve efficiency and effectiveness of screening.
- Facilitate collaborative networks of study sites.



3. Engage Local Communities & Support Participants

Strategic Priorities:

- Develop equitable and sustainable community partnerships to build trust and shared ownership of research mission.
- Promote health and science literacy in the community with a focus on cognitive health.
- Expand trial design to encourage participation of more diverse communities.
- Facilitate diverse participation by providing support and audience-specific recruitment and retention strategies.
- Identify and prioritize available resources to develop community partnerships and support participants.



4. Develop an Applied Science of Recruitment

Strategic Priorities:

- Develop baseline measures and evaluate and optimize effectiveness of outreach and recruitment strategies.
- Create, disseminate, and continuously improve evidence-based recruitment resources.



Roles for Stakeholders – Gov Agencies

- Signal priorities in funding opportunity announcements or procedures
- Shape application submission and review requirements
- Work directly with investigators in cooperative agreements
- Collect and disseminate evidence-based resources in a central location
- Support evaluation efforts and compilation of the evidence base
- Provide a national voice to communicate priorities



Roles for Stakeholders – Advocacy Organizations

- Organize national, regional, and local awareness campaigns
- Build and maintain relationships with other stakeholder groups
- Create and adapt materials and resources for study site use
- Collect and disseminate evidence-based resources
- Support or conduct community needs assessments and evaluations
- Provide a national voice to communicate and reinforce priorities.



Roles for Stakeholders – Researchers, Study Sites, Institutions

- Plan and budget for the priorities outlined in the Strategy
- Prioritize and implement improvements in study site capacity and workforce to support diverse recruitment
- Develop local-level community partnerships, build trust, involve community in the research enterprise
- Develop referral networks with primary care providers and other study sites
- Implement trial designs and organizational incentive structures that maximize diverse participation.



Roles for Stakeholders – Community Orgs

- Participate in community advisory boards
- Build relationships with researchers and study sites
- Host community events or offer locations for study outreach
- Become involved in the research enterprise



Roles for Stakeholders – People with Dementia, Caregivers, Families

- Share their experiences with others
- Ask primary care physicians for screening or referrals to clinical research opportunities
- Participate in clinical research
- Become peer mentors for others considering research participation
- Provide input and feedback to researchers and study sites
- Help study sites build community partnerships



NIA's Role in Implementation



Convene and facilitate

- Continue to convene and facilitate stakeholders to implement tactics outlined in the National Strategy

Targeted outreach

- Continue to increase awareness, conduct targeted outreach efforts

Enhance and share the evidence base

- Support evaluation of and disseminate research on effective recruitment strategies

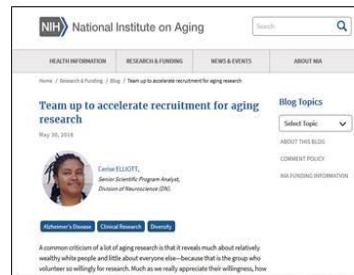
Funding and policy

- Address recruitment challenges through funding initiatives and policies
- Support research infrastructure enhancements



Funding opportunity for community engagement

- [Examining Diversity, Recruitment and Retention in Aging Research \(PAR-18-749\)](#)
- Encourages building new, **collaborative teams** to target gaps in recruitment and retention methods and outcomes
- Support for establishing **community infrastructure** needed to accelerate studies



Read more at:
<https://www.nia.nih.gov/research/blog/2018/05/team-accelerate-recruitment-aging-research>



Social Media Outreach

Join us on Twitter
Tuesday October 23
to celebrate
#ResearchDiversity

A graphic for social media outreach. The background is dark with a grid of colorful, glowing circles in shades of yellow, green, and blue. The text is white and bold. It says "Celebrate diversity in research!" at the top. Below that, it says "JOIN THE CONVERSATION OCTOBER 23, 2018" and "#RESEARCHDIVERSITY". At the bottom, it says "Learn from the experts on diversity in research training, study recruitment, and more." and "@ALZHEIMERS_NIH". The NIH Aging logo is in the bottom right corner.



We've only just begun... We're all in this together

What can each of us do
to move Alzheimer's &
related dementias
research forward?

