COMMUNITY FIRST:
ALZBrainTrust Engagement Guide

ALZBRAINTRUST

ALZHEIMER'S ASSOCIATION

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Message from Leadership

We are at a pivotal moment in the fight against Alzheimer's and other dementias. Breakthroughs in research, diagnostics, and treatment are accelerating, and for the first time, multiple disease-modifying therapies are offering new hope to individuals and families. Yet progress alone is not enough. These advances can only improve public health if they are accessible, trusted, and relevant to all communities.

ALZBrainTrust was created to meet this moment, reflecting a shift from traditional research toward community-centered engagement—where trust is built over time, lived experience is valued, and communities are true partners. Working alongside trusted leaders, it co-creates approaches grounded in the realities of historically under-resourced and disproportionately affected communities. Across three community-based hubs, this work has shown what's possible when communities lead—serving as "bridge builders" between research and lived experience, strengthening trust, expanding awareness of brain health, and informing more equitable approaches to dementia research.

The Alzheimer's Association's commitment to equity is embedded across all our work—from the research we fund, to the policies we advance, to the care and support we provide. Through partnerships with national and community-based organizations, we are reaching more people, in more places, and in ways that reflect the diversity and resilience of our communities. Together, we are building a movement that is both inclusive and actionable.

Yet, even as we celebrate meaningful progress, the urgency remains. Millions of people are living with dementia today, and millions more are caring for loved ones. The impact of this disease continues to grow, and so must our resolve to ensure that no community is left behind.

This Engagement Guide is part of that commitment. It is designed to share what we have learned through ALZBrainTrust, to elevate the expertise of our community partners, and to promote more equitable engagement in research. Whether you are a community leader, partner organization, or researcher, we invite you to use this guide as a resource—and as a call to action.

Together, we can ensure that the promise of today's scientific progress leads to generalizable outcomes —and brings us closer to a future without Alzheimer's and all other dementia, for all communities.

Sincerely,

Carl V. Hill, Ph.D., MPH
Chief Diversity, Equity and Inclusion Officer

ALZBrain Trust: Pursuing Equity in Dementia Clinical Research Through Regional Strategies

Launched in October 2023, the goal of ALZBrainTrust is to develop a flexible, scalable and national model to increase representation in clinical trials research for Alzheimer's and other dementias. The model is informed by community partners from Black/African American and Hispanic/Latino populations in order to accurately reflect and address their existing participation barriers while fully utilizing community and cultural assets. Dissemination includes the sharing of findings with researchers, community partners, pharmaceutical industry, funders, policymakers and other partners.

For this work, the Alzheimer's Association identified three pilot regions, or "hubs," in metropolitan areas: Chicago, Houston and Los Angeles. Hubs were selected based on their having large, underrepresented populations with a high number of individuals age 65 and older, as well as for the presence of a robust local infrastructure, longstanding Alzheimer's Association chapter relationships, and the capacity to facilitate deep, community-grounded work. Each hub comprises the local Association chapter (with leadership by the chapter executive director and chapter Diversity, Equity and Inclusion (DEI) directors), a researcher from a local research institute and community partners. Hub researchers were recruited from respected academic institutions within each area. The academic leaders collaborate closely with Association staff and community partners to guide the regional strategy, identify theoretical frameworks, conduct a literature review, and co-design an engagement process that reflects local needs and conditions.

The Importance of Equity in Dementia Clinical Research: A Literature Review

The burden of dementia impacts underrepresented and underserved communities disproportionately. Black/African Americans are 1.6-2 times as likely as non-Hispanic Whites (Whites) to develop Alzheimer's disease.[1] They also experience diagnostic delays that are 11% longer than for Whites.[2] Risk rates vary between different Hispanic/Latino heritage groups,[3] but the overall risk is 1.5 times that of Whites,[4] and their diagnostic delays are 40% longer.[2] Delayed care leads to more limited treatment options, less prepared and more stressed family caregivers, and missed opportunities to enroll in clinical research.

A wide range of factors contributes to these disparities. Diseases that increase the risk of cognitive decline (e.g., heart disease, diabetes) occur at higher rates among Black/African Americans and Hispanic/Latinos compared to Whites.[5] Greater socioeconomic and psychosocial stressors, along with lower access to quality healthcare, contribute both to the occurrence of dementia-disposing diseases and to dementia rates themselves.[6]

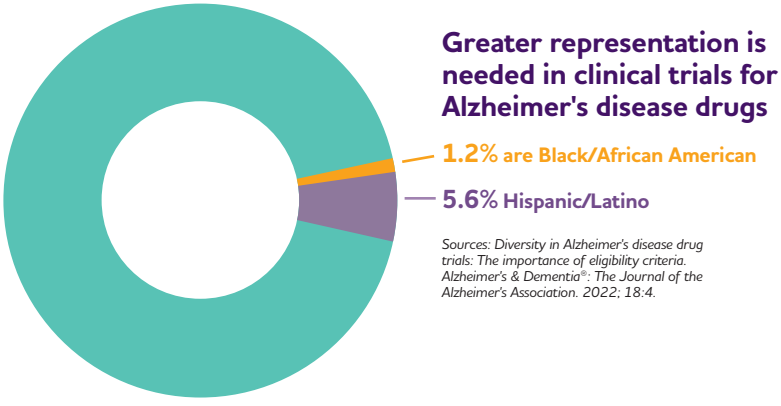
Clinical Research Participation is Lower.

Black/African Americans and Hispanic/Latinos make up approximately 13% and 18% of the U.S. population, respectively, but only around 5% of dementia trial participants. Drug trial participation is especially critical now that U.S. Food and Drug Administration (FDA)-approved medications are available that can slow disease progression, and dozens more medications are being tested. Yet, in a study of 101 of these trials, the median percentage of White participants was 94.7%.[7]

The Impact of Underrepresentation on Science and Outcomes.

Lack of representation by any population, and especially the populations at highest risk, is a study design flaw that threatens the validity of the results for all populations. Diagnostic protocols will be more likely to miss early symptoms and cases of mixed dementia; pharmacological treatments may overlook key metabolic and genetic differences between patients; and our understanding of factors that confer risk and resilience will be less complete. In the end, underrepresentation in research increases healthcare costs and lowers the quality of life of the U.S. population.

The aging of Americans adds significant urgency to this issue. By 2060, the number of Americans aged 65 and older will nearly double to almost 25% of the total population.[8] As the fastest-growing aging populations, Black/African Americans and Hispanic/Latinos are expected to experience the steepest rise in dementia. Projections indicate that there will be nearly a nine-fold increase in the number of Hispanics living with Alzheimer's and other dementias by 2060, resulting in $2.35 trillion in cumulative societal costs.[9]



Sources: Diversity in Alzheimer's disease drug trials: The importance of eligibility criteria. Alzheimer's & Dementia®: The Journal of the Alzheimer's Association. 2022; 18:4.

Barriers to Participation.

Numerous studies highlight significant barriers to dementia research participation. Two overarching categories were identified for this review: 1) structural and institutional, and 2) cultural and historical.

STRUCTURAL AND INSTITUTIONAL BARRIERS

- **Restrictive Eligibility Criteria.** Black/African Americans and Hispanic/Latinos have higher rates of the medical conditions (e.g., heart disease, diabetes, hypertension, asthma) and their associated medications that are sometimes used to limit research participation,[10] even though eligibility criteria of this type often have little scientific justification.[11] Restrictive eligibility criteria enforce homogenous samples that do not reflect the health profiles of real-world patients, so careful consideration must be taken when deciding who will and will not be eligible for a study.

- **Research Workforce Diversity.** Workforce diversity is beneficial to scientific progress and critical to reducing scientific mistrust, but the U.S. scientific workforce (i.e., physicians, research teams, study review panels, institutional review boards) has never reflected the population. Only around 8% of full professors are Black/African American or Hispanic/Latino,[12] and National Institutes of Health (NIH) grant submissions by White researchers are 1.7 times more likely to be funded than those by Black/African American researchers.[13] This leads to blind spots in study design and implementation, such as rejecting community-led designs and culturally sensitive research strategies that fall outside of traditional academic norms.

- **Socioecological and Logistical Burdens.** The demands of research participation can pose significant barriers for working-class families, single caregivers and rural residents. Many study sites are in affluent or academic medical centers far from underresourced neighborhoods. Study visits may occur only during business hours or in distant settings while offering limited or no transportation support, childcare or eldercare. Web-based portals and email communications are thought to increase accessibility, but they may not help older adults or immigrant households with limited broadband and tech fluency.

- **Linguistic Exclusion.** Language barriers arise for both verbal communications and the availability of translated recruitment, consent and other study materials. Language barriers are particularly important in dementia research, where participants take cognitive tests and are evaluated for their ability to provide consent.[14] Translated materials must be culturally appropriate to avoid confusion and even insult.[15]

CULTURAL AND HISTORICAL BARRIERS

- **Mistrust Rooted in Historical and Ongoing Harm.** A significant barrier to Black/African American and Hispanic/Latino research participation is mistrust of academic and research institutions investigators and fears around immigration status.[16,17] Centuries of exploiting the bodies and lives of non-White Americans for "science" has created deep mistrust, especially as discrimination and health disparities continue to occur in terms of pain management,[18,19] maternal mortality,[20] access to specialty care[21] and others.

- **Health Literacy.** The ability to obtain, understand, and take action regarding basic health-related information and services is significantly lower among older adults and those of lower socioeconomic status.[22] Lower health literacy is related to adverse health outcomes, including less use of preventive care,[23] lower medication adherence[24] and higher healthcare costs.[25] Clear, plain-language information is needed that explains the purpose of clinical trials, the protections in place and the potential benefits and risks.

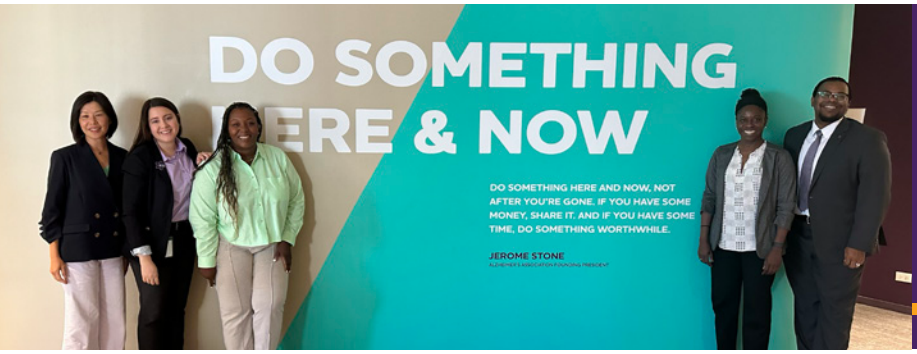
- **Stigma and Spiritual Framing.** Black/African Americans may be particularly impacted by negative stigma relating to cognitive decline and dementia.[26] Stigma often leads to delays in seeking a diagnosis, as well as minimizing symptoms and avoiding sharing one's health concerns with friends and loved ones.[27] Working with faith communities helps reduce stigma around dementia while providing spiritual, social and material support.[28,29]

> "I don't want to be a statistic.
> **I want to be part of the solution."**
> — Participant, Houston Listening Session

CONCLUSION:

Research underrepresentation is a product of institutional design and culture. Only through structural reforms and equitable engagement strategies can we fix a scientific enterprise that, by not serving all equally, serves no one fully. The ALZBrainTrust is a response to this challenge.

The theoretical framework underpinning ALZBrainTrust is Community Based Participatory Research (CBPR).[30] CBPR focuses on building collaborations between community and academic partners to address all aspects of research, including identifying and prioritizing issues, designing recruitment and data collection procedures, determining how and when to intervene, and interpreting and disseminating results. A recent review found that 85% of studies that used CBPR met their recruitment diversity goals.[31] CBPR methods include more consistent communications with community leaders, including community members as advisors, ensuring communications fit



"Stigma is powerful.
But so is hope."
- Chicago Community Conference Attendee

Listening as Leadership: Sites and Their Processes

By July 2025, each hub had recruited community partners, launched coalition kickoff meetings that brought researchers and community partners together, conducted partner and community listening sessions, and completed their own literature reviews. Findings were then synthesized for the themes, insights and regional distinctions that were used to refine each hub's approach.

The following provides additional details about each of these components, after which we provide an overview of the specific activities undertaken by each hub.

GENERAL ALZBRAINTRUST HUB PROCESSES AND ACTIVITIES:

- **Community Partners.** Community partners were selected based on their trust within the community, cultural expertise, and ability to inform dementia research through grounded knowledge.

- **Literature Reviews.** Working with Association staff and community partners, each hub researcher conducted a literature review aimed at informing local strategy development, contributing to scholarly discourse, serving as a foundational document to justify ALZBrainTrust strategies and guiding subsequent research efforts.

- **Partner and Community Listening Sessions.** Listening sessions with community residents were held to learn about perceptions and attitudes toward clinical research. Listening sessions emphasized dialogue over data collection and focused on lived experience, trust, institutional memory and cultural framing of clinical research and dementia. Where appropriate, listening sessions were audio recorded and transcribed.

Specific Activities Undertaken by Each Hub:

CHICAGO

Indiana University School of Health Bloomington researcher Dr. Priscilla A. Barnes leads the Chicago hub. An associate professor of Applied Health Science and founding director of the Center for Community-Engaged Dissemination and Implementation Research (CCEDIR), Dr. Barnes focuses on community-academic partnerships, rural health and public health systems.

The Chicago hub advanced a coordinated set of activities to strengthen community-engaged strategies for increasing awareness, trust and participation in dementia clinical trials among Black/African American and Hispanic/Latino communities. The four community partners include Messiah Temple Missionary Baptist Church of Chicago; RUSH Alzheimer's Disease Center (ADC); Telpochcalli Community Education Project (TCEP); and the University of Chicago Healthy Aging and Alzheimer's Research Care (HAARC) Center. In addition to two listening sessions, the partners met five times throughout the project for dialogue, trust-building, and to provide iterative feedback on frameworks and approaches.

SPECIFIC ACTIVITIES INCLUDED:

- **Strategic Doing Session.** Strategic Doing is a relationship-centered approach to planning and collaboration aimed at helping groups move from ideas to coordinated action. The approach guides partners through identifying assets, linking and leveraging those assets in new ways, and co-designing affordable, high-impact opportunities. Practical action is emphasized through the selection of a Pathfinder Project, a simple achievable step that tests a new idea while deepening trust and collaboration. Each Pathfinder Project includes an action plan with check-ins to build stronger habits of collaboration over time.

Held at Mesler Kitchen in Chicago, the session included 11 cross-sector partners representing the Association (both national and Illinois Chapter teams), HAARC, Rush ADC/Latino Core, TCEP and the Messiah Temple M.B. Church.

Key outcomes included:

- » Identifying and mapping 104 community assets across people, programs, places, knowledge and networks, such as bilingual outreach staff, faith leaders, caregiver support circles, barbershops, cultural centers and clinical research programs. This asset library will serve as a searchable information hub, a repository of culturally tailored materials, and a resource for training, onboarding and conversation starting. Session teams then generated six opportunity concepts, such as Quilts & Conversations (story-telling and quilting), Fit for Thought (fitness plus U.S. POINTER study education) and church Pulpit Panels.
- » Developing a Pathfinder Project. The BridgeBuilders Clinical Research 101 is a two-part research series offered at Messiah Temple M.B. Church in partnership with HAARC. For example, 10 Warning Signs of Alzheimer's and Dementia/What Is ALZBrainTrust was presented to 36 participants, four of whom signed up for a HAARC study.

- **Literature Review.** Dr. Barnes' literature review examined how the Asset-Based Community Development (ABCD) framework (see Section V, and related frameworks have been applied in health equity research over the past 20 years, with particular attention to implications for dementia research.

- **Qualitative Interviews.** In-depth, semi-structured interviews are being held with community outreach persons to better understand how to engage African American and Latino communities in dementia research. Questions focus on the lived experience of outreach work, the role of trust-building, navigating community cultural dynamics, collaborating with researchers, step-by-step methods to move participants from initial contact to enrollment, and how informal community leadership, warm handoffs and retention activities shape long-term participation. Findings will inform a future guidebook or practice brief for researchers working in diverse communities.

- **Release the Silence Conference Surveys.** Release the Silence is an annual community event hosted by the Association and HAARC to raise awareness about dementia and memory loss in the Black/African American community. Participants (109 of 500 attendees) at the 2025 event were surveyed on their awareness of dementia research and clinical trials. Most were only somewhat or slightly aware, and the largest group reported no familiarity with clinical trials. To improve engagement, participants sought culturally relevant outreach and education, increased access to local research opportunities, community-based presentations, and opportunities to hear directly from research participants.
  In 2026, more than 600 individuals attended the conference at the University of Illinois Dorin Forum, where they heard from presenters, including about TrialMatch, a free, easy to use service from the Association that helps persons find clinical research studies that may be a good fit for them. When asked who they trusted most for information regarding their loved one's diagnosis, attendees shared that, after their clinician, they trusted the Alzheimer's Association, followed by their faith leaders. This is a significant finding given that, when the Association first offered Release the Silence four years ago, attendees reported that they had no trusted source of information. Attendees credited this to the relationships the Association has made in the community.

- **Piloting a Spanish-language Research Conversations Presentation.** The Association's presentation, Research Conversations, is used to raise awareness in under-resourced and disproportionately impacted communities about the need for greater representation in dementia clinical trials. The Chicago hub is to pilot a Spanish-language version within Spanish-speaking communities.

HOUSTON

The Houston hub is led by Dr. Luis D. Medina, an assistant professor of Psychology and director of the Collaborative on Aging Research and Multicultural Assessment (CARMA) at the University of Houston. A clinical psychologist and cultural neuropsychologist, he focuses on the cultural neuroscience of aging and clinical assessment and diagnosis in underrepresented populations, particularly in the context of Alzheimer's disease and Hispanic/Latino populations.

The Houston hub worked with four community partners: Community Family Centers (8 participants); Wheeler Avenue Baptist Church (10 participants); East End Community Collaborative (15 participants); and the Archdiocese of Galveston-Houston (10 participants). The community partners advocated for separate sessions held in their preferred neighborhood or space to reflect their distinct constituencies. One listening session was co-hosted by two community partners, demonstrating cross-organizational collaboration.

SPECIFIC ACTIVITIES INCLUDED:

- **Listening Sessions.** Houston's listening sessions elicited shared themes (e.g., education as a prerequisite for engagement) and differing priorities (e.g., the most pressing issues identified by caregivers differed from that of physicians and clinical staff) around cultural and structural barriers.

They also identified short-term solutions versus long-term strategies. Short-term solutions (i.e., needs that can be realistically responded to in the next six months) included:

- Leveraging Association education infrastructure with a focus on prevention and positive framing.
- Increasing visibility and trust through banners, Helpline signage, and flyers in churches and in community and senior centers.
- Event-based community engagement through aligning campaigns with relevant local events.
- Streamlining access by simplifying the request for speakers and information sessions and encouraging drop-in-style resource sharing with trusted local partners.

Long-term strategies, (i.e., plans with a 6-18-month timeframe), included:

- Developing a Community Hierarchy of Needs framework that prioritizes education, safety, trust and research participation.
- Strengthening clinical and caregiver pathways by empowering primary care providers to conduct cognitive screenings and building up caregiver support systems (e.g., digital support and in-person groups).
- Expanding incentive structures for research participation to screening access, wellness checks, peer support and compensation.
- Engaging community health workers through training and certification and by including university students as outreach and education ambassadors.
- Bridging the gap between researchers and community through public meetings and "rapid response" community educators.

- **Literature Review.** Dr. Medina examined the relevant literature around recruitment disparities in Hispanic/Latino communities and discussed how the increased dementia risk in Hispanic/Latino communities is shaped by intersecting biological, contextual and structural factors.

- **Setting strategic priorities.** The following strategic priorities were set: awareness and education, caregiver support, community trust, prevention messaging, youth and intergenerational engagement, culturally relevant materials and event-driven outreach.

- **Community education and engagement.** Several watch parties with 20-40 attendees each were hosted for "Memories of My Grandfather," a mini-telenovela created to spark conversation around Alzheimer's disease in Hispanic/Latino communities. Informational outreach was conducted at cultural events such as Día de los Muertos, and a dementia screening paired with a clinical trials panel was held at the Houston Health Museum. Education was delivered through virtual and in-person sessions with senior groups, faith-based organizations and the archdiocese, while larger efforts included a Spanish-language brain health conference, resource fairs with research representation and community gatherings. Regular engagement at Family Community Centers and East End Collaborative events — reaching hundreds through health/food fairs and local programming — also supported the development of community health worker champions and expanded access to Alzheimer's education and research awareness.

LOS ANGELES

The Los Angeles hub is led by Dr. Karen D. Lincoln from the University of California Irvine's Joe C. Wen School of Population and Public Health. Dr. Lincoln is a professor in the Department of Environmental and Occupational Health, director of the Center for Environmental Health Disparities Research, and founder and director of Advocates for African American Elders. An expert in social determinants of health disparities, her research, writing and advocacy are rooted in the Black American experience and span social work, sociology and gerontology.

Los Angeles has one of the strongest community-based, faith-based, social and civic infrastructures in the nation for diverse, Black/African American engagement. Churches, fraternities, community organizations and residents are already mobilized and eager for partnership, largely due to the coalition-building activities of Advocates for African American Elders. The Los Angeles hub began with 10 invited partners and contracted with five: Advocates for African American Elders (AAAE); Alpha Phi Alpha Fraternity Inc., Beta Psi Lambda Chapter; Grand Park Foundation; Grant African Methodist Episcopal (AME) Church; and the South Bureau Ministerial Alliance.

SPECIFIC ACTIVITIES INCLUDED:

- **Listening Sessions.** Two in-person listening sessions and a virtual meeting were held. Across all three, more than 50 community members, faith leaders, advocates and researchers shared their perspectives. The sessions consistently reinforced that equity, trust and cultural alignment must be foundational in brain health research and engagement. Key recommendations for engaging communities in research include:
  - » Clear, accessible explanations of data use and genetic testing.
  - » Regular presence from research institutions.
  - » Culturally relevant outreach by researchers who represent Black communities.
  - » Youth-inclusive communication strategies.
  - » Opportunities to help shape research from the ground up.

Short-term solutions included:

- A regular engagement cadence (e.g., every 30-45 days) to build a sustained community presence.
- Developing dementia-friendly toolkits for churches.
- Developing youth-facing materials such as animations, social media and talks.
- Holding intergenerational brain health storytelling sessions.
- Developing What Happens to My Data fact sheets in plain language.
- Highlighting community leaders' contributions and expertise.

Long-term strategies included:

- Forming a Community Advisory and Co-Design Board with representatives from community stakeholders.
- Conducting community asset and partner mapping.
- Training community partners as trusted messenger and research navigators.
- Co-designing a guide on how to integrate community voices into trial pipeline design.
- Partnering with schools, youth ministries, fraternities, sororities and after-school programs to expand youth and intergenerational engagement.

FOUR RESEARCH RECRUITMENT STRATEGIES WERE PRIORITIZED, INCLUDING:

1) Organizing research events at accessible locations (e.g., Alpha Phi Alpha House).
2) Integrating trusted voices (clinicians, community leaders, media).
3) Ensuring consistency in community engagement and education.
4) Publishing stories in ethnic media to highlight community assets.

- **Literature Review.** Dr. Lincoln reviewed the literature on the persistent racial disparities in dementia incidence and clinical research participation, including the structural inequities and socioeconomic barriers driving them. The review then highlighted community engagement strategies that show measurable improvements in recruitment and retention of minority populations and discussed important gaps in the literature.

- **Community Education and Outreach.** Research presentations, symposia and community gatherings (like Taste of Soul, which engaged over 800 attendees) have helped reach diverse audiences, while faith-based initiatives, like Dementia Friendly Sundays and partnerships with organizations such as Alpha Phi Alpha and the Southern Bureau Ministerial Alliance, have deepened community impact. Ongoing activities include research celebrations, film screenings and conferences

"We honor the three Ts: time, talent, treasure. What's missing and equally important is the temple — people's spirituality."

- Pastor Dr. Keith B. McGee, Temple M. B. Church of Chicago, Community Partner

Engagement Models

Rather than prescribing a single framework, ALZBrainTrust empowers researchers and community voices to develop targeted strategies. Each model is discussed below.

CHICAGO: ASSET-BASED COMMUNITY DEVELOPMENT (ABCD) FRAMEWORK.

Community-based organizations reported that residents often turned to church leaders or neighbors for advice before reaching out to medical professionals, underscoring the need for engagement strategies that start within trusted community networks. The Asset-Based Community Development (ABCD) framework repositions community members as co-owners of the engagement process, drawing on local assets, storytelling traditions and culturally resonant networks to drive inclusion.[32] ABCD focuses on identifying and mobilizing community strengths, such as faith-based institutions, intergenerational knowledge and trusted local leaders to build culturally grounded engagement strategies. Shifting the focus from deficit-based recruitment to relational, strength-based research collaboration can help build a replicable structure for embedding research into community ecosystems.

Key elements include:

- Storytelling as an engagement method, allowing families to voice experiences with memory loss in their own terms.
- Faith-based outreach that integrates dementia education into existing spiritual care networks.
- Community-led digital dissemination, ensuring that materials reach people where they already gather information — whether through WhatsApp groups or church livestreams.

HOUSTON: ACCELERATOR MODEL

Community members cited inflexible clinic hours, untranslated consent forms and the absence of Spanish-speaking providers as key reasons for delayed diagnosis and reduced clinical research participation. An Accelerator Model of community development relies on cohorts to provide mentorship and networking to scale new initiatives and is often structured into phases that can help connect teachings with practice.[33,34]

LOS ANGELES HUB: JUSTICE-CENTERED COMMUNITY-BASED PARTICIPATORY ACTION (CBPA) FRAMEWORK

Focus group participants expressed fear of being "used for experimentation" or "not taken seriously," especially in relation to cognitive impairment. The Justice-Centered CBPA framework directly addresses mistrust born from racism and exclusion, recognizing that Black/African American communities are not “hard to reach” but rather are systematically ignored and misunderstood. The framework centers the legacy of systemic racism, cultural trauma and resourcefulness in Black communities, pairing long-term trust-building with an explicit call for structural reform across the research process. Instead of framing research as a service to the community, Lincoln’s team frames it as a partnership where communities are active co-designers of every aspect of outreach and study implementation. Engagement is built through longstanding, reciprocal partnerships with trusted institutions, such as churches, barbershops and grassroots organizations.

The model includes:

- Culturally tailored recruitment materials and diagnostics that reflect linguistic and cultural norms.
- Community advisory boards that provide structural feedback and ensure accountability.
- Visible representation of Black/African American researchers and staff, creating familiarity and relational safety.

SUMMARY:

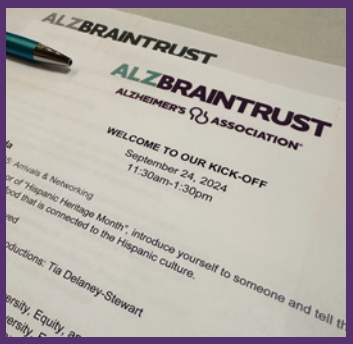
These frameworks challenge the research community to build new approaches rooted in reciprocity, representation and reparation to improve the three primary components of the research infrastructure: knowledge (e.g., culturally rooted expertise, community insights and historical context); resources (e.g., access to physical spaces, funding and logistical tools such as mobile units and bilingual staff); and power (e.g. who has authority to shape the research agenda, co-create protocols and determine what outcomes matter).

Practice-Based Recommendations:

THE ALZBRAINTRUST NATIONAL STRATEGY

ALZHEIMER'S ASSOCIATION

The following provides **10 targeted,** actionable recommendations to **strengthen community engagement** for facilitating diverse research recruitment. These build directly on what the hubs have found effective while addressing gaps and barriers surfaced through experience.



1

Embed recruitment within existing programs and build direct research opportunities into all engagement activities.

Ensure every outreach event includes a clear, actionable step for research participation. This can include on-site sign-up forms, QR codes linking to studies, or staff available to screen for eligibility. Standardize a requirement that all education and outreach efforts include a defined recruitment pathway to reduce drop-off between interest and enrollment. Integrate these opportunities into ongoing activities, such as caregiver programs, faith-based gatherings and community organization services. Expand referral pathways by working more closely with healthcare providers and clinics, and create simple workflows for partners to refer individuals directly into research opportunities.

2

Formalize a community ambassador model.

Identify and train trusted community members (e.g., faith leaders, caregivers, community health workers) to serve as ongoing referral partners. Provide them with simple talking points, recruitment materials and feedback loops so that they can consistently connect individuals to research opportunities. Consider stipends or recognition structures to sustain participation.

3

Shift to a smaller but recurring engagement cadence.

Trust is built through ongoing, reciprocal relationships, not short-term outreach. Replace or supplement large, one-time events with smaller, regularly scheduled touchpoints (e.g., monthly sessions at community sites and/or event-based engagements). Develop a shared engagement calendar and use hybrid (in-person plus virtual) approaches to maintain consistent visibility while managing staff capacity and minimizing burnout.

4

Community leadership should shape research from the start.

Include community partners and members early and consistently in the research process so that they can contribute their ideas and knowledge to the study design, identification and prioritization of outcomes, outreach materials and methods, and data-sharing practices.

5

Standardize straightforward research communication and transparency practices.

Research must benefit communities, not simply extract data. Develop a set of plain-language materials that clearly explain study purpose, expectations, risks and data privacy. Build a process for routinely sharing study updates and results back to community partners and interested participants through presentations, summaries or community meetings to reinforce trust and accountability.

6

Expand multilingual and culturally tailored materials.

Audit current materials and prioritize translation into commonly spoken languages (e.g., Spanish), along with access to interpreters at key events. Work with community partners to adapt messaging to reflect cultural values, norms and preferred communication styles to improve resonance and comprehension.

7

Pilot new outreach strategies for under-engaged groups.

Develop targeted and innovative initiatives to reach new populations not currently engaged, such as youth and families. Test intergenerational approaches (e.g., youth educating older relatives about research) and partnerships with schools or community programs to expand awareness and future recruitment pipelines. Storytelling, the arts and other non-clinical communication strategies can help reduce stigma and fear while providing education and opportunities for support.

8

Reduce hurdles that prevent people from joining.

Incorporate practical supports into recruitment planning, such as transportation assistance, flexible scheduling and accommodations for caregivers. Where feasible, bring research activities directly into community settings through mobile or pop-up models.

9

Strengthen staffing and shared resources.

Assess staffing gaps and advocate for dedicated roles focused on community engagement and recruitment, including by hiring representatives of that community wherever feasible. Develop shared, ready-to-use toolkits (e.g., outreach templates, multilingual materials) across hubs to reduce duplication and increase efficiency, especially given funding and capacity constraints.

10

Track and optimize recruitment outcomes.

Implement simple tracking systems to measure the conversion from outreach activities to research enrollment (e.g., attendance → inquiries → sign-ups). Use this data regularly to identify which engagement strategies are most effective and adjust resource allocation accordingly.

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