RCCN Workshop: Tools and Barriers Multidisciplinary Research

Including The Community in Multidisciplinary Teams

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SCHOOL OF MEDICINE

INDIANA UNIVERSITY

Outline/Objectives

- Define the ***need***
- Describe the ***why*** and the ***value***: Community Based Participatory Research (CBPR)
- Discuss ***opportunities*** for community inclusion in aging research

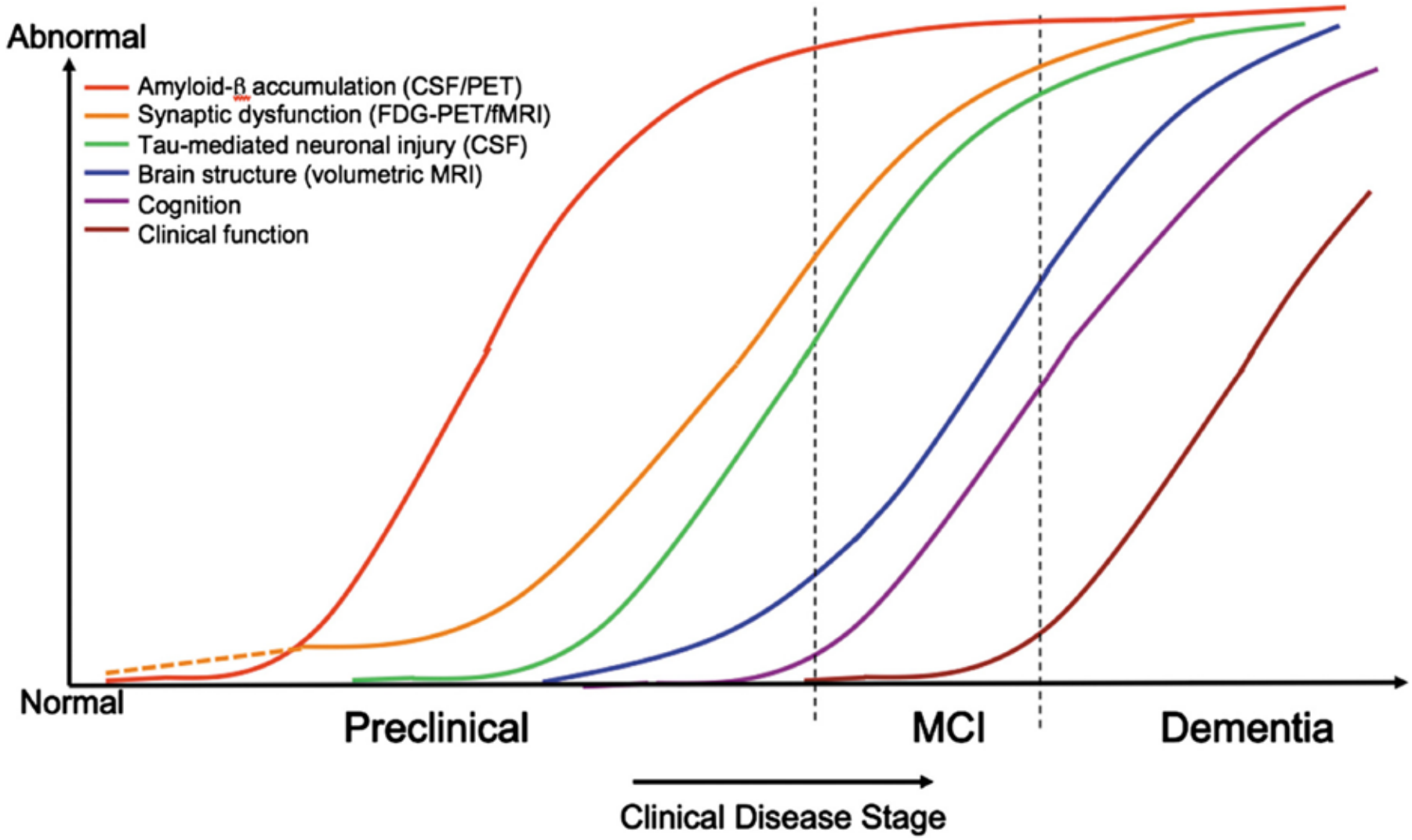
"Community is much more than belonging to something; it's about doing something together that makes belonging matter." Brian Solis



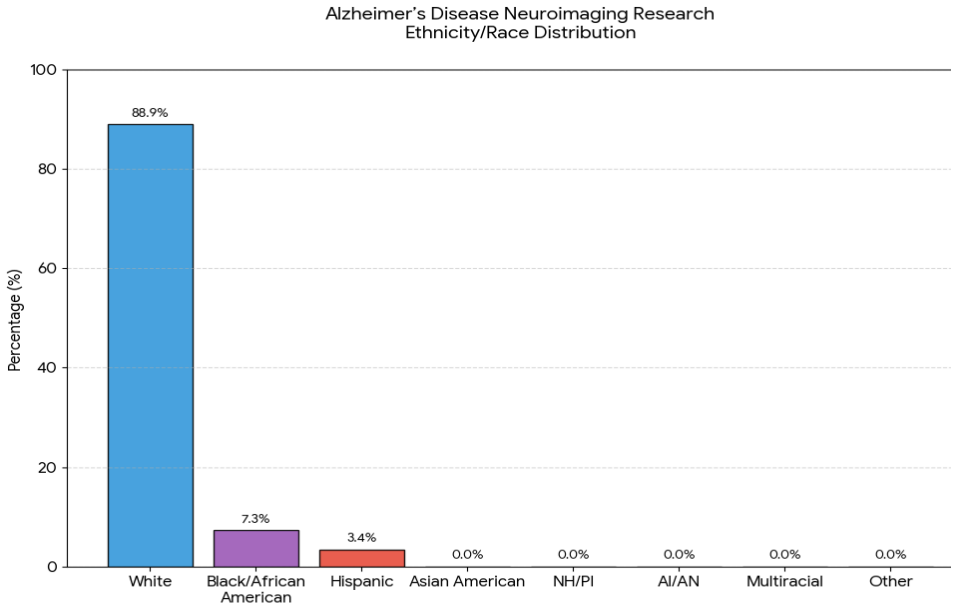
" Coming together is a beginning; keeping together is progress; working together is success." Henry Ford

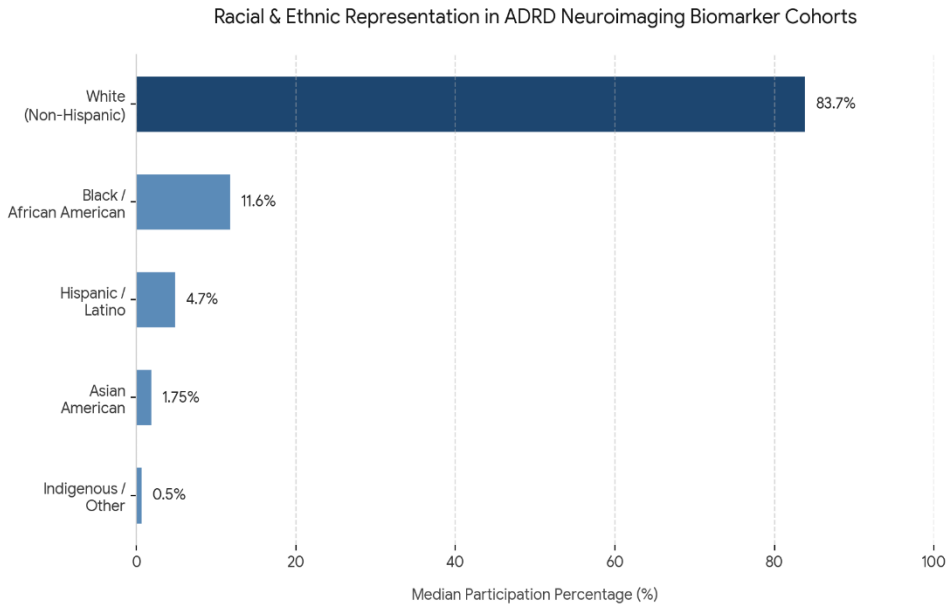
"The power of community to create health is far greater than any physician, clinic, or hospital." Mark Hyman

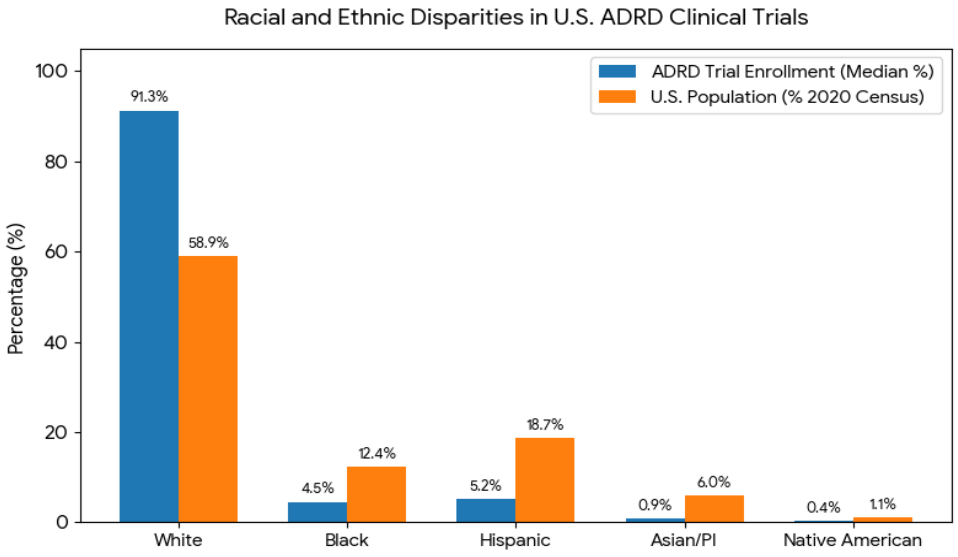
Professional Identity



(Better., 2023; Jack et al, 2014)







(Bubu, 2026; Lim et al, 2023; Han et al., 2022)

Category	Theme / Area	Key Insight	Implication for Practice
Overall Evidence	ADRD Research (Recruitment, Retention, Inclusion)	Limited quantity and quality of available evidence	Constrain development and implementation of best practices
Barrier	Mistrust	Lack of trust in research institutions and processes	Reduces willingness to participate
Barrier	Stigma & Limited Research Literacy	Misunderstanding of research and fear of participation	Limits informed decision-making and engagement
Barrier	Logistical & Financial Constraints	Transportation, time, and cost-related challenges	Creates access barriers to participation
Barrier	Communication Gaps & Lack of Team Diversity	Ineffective communication and limited representation within research teams	Weakens outreach and participant connection
Barrier	Systemic-Level Barriers	Institutional and structural obstacles	Sustains inequities in research participation
Facilitator	Culturally Tailored Outreach	Engagement strategies aligned with community values and norms	Improves trust and participation
Facilitator	Long-Term Community Partnerships	Sustained collaboration with community organizations	Strengthens recruitment and retention over time
Facilitator	Inclusive Study Design	Research approaches prioritizing diversity and inclusivity	Enhances representation and equity in study outcomes

What Research Shows	Why It Matters	Key References
Lower rates of amyloid positivity among Hispanic and Black individuals during AD biomarker screening	Amyloid-focused therapies and trials may benefit only a subset of patients	Morris JC, Schindler SE, McCue LM, et al. Assessment of Racial Disparities in Biomarkers for Alzheimer Disease. JAMA Neurol. 2019;76(3):264–273. doi:10.1001/jamaneurol.2018.4249
Greater prevalence of vascular risk factors (hypertension, diabetes, ischemia) among Hispanic and Black populations	Cognitive impairment may arise through amyloid-independent pathways	Gottesman RF, Albert MS, Alonso A, et al. Associations Between Midlife Vascular Risk Factors and 25-Year Incident Dementia in the Atherosclerosis Risk in Communities (ARIC) Cohort. JAMA Neurol. 2017;74(10):1246-1254. doi:10.1001/jamaneurol.2017.1658
Underrepresented groups may fail amyloid thresholds required for AD clinical trial enrollment	Important populations risk exclusion from emerging therapies	Cummings J, Apostolova LG, Rabinovici GD, et al. Lecanemab: Appropriate Use Recommendations. Journal of Prevention of Alzheimer's Disease. 2023;10(3):362–377.
Social determinants such as education, socioeconomic status, and access to care influence dementia risk and diagnosis	Broader and more inclusive approaches to diagnosis and treatment are needed	Livingston G, Huntley J, Sommerlad A, et al. Dementia prevention, intervention, and care: 2020 report of the Lancet Commission. The Lancet. 2020;396(10248):413–446.
Research suggests non-AD contributors to cognitive impairment may be more prevalent in understudied groups	The field should expand beyond amyloid-centric models to better understand dementia across populations	Wilkins CH, Windon CC, Dilworth-Anderson P, et al. Racial and Ethnic Differences in Amyloid PET Positivity in Individuals With Mild Cognitive Impairment or Dementia: A Secondary Analysis of the Imaging Dementia–Evidence for Amyloid Scanning (IDEAS) Cohort Study. JAMA Neurol. 2022;79(11):1139–1147. doi:10.1001/jamaneurol.2022.3157

(Better., 2023; Jack et al, 2014)


"Breakthroughs do not happen in silos.
True innovation lives at the intersection where
science meets the lived human experience."
COMMUNITY CENTER
The intersection of innovation.
Community-Academic Partnerships

"Partnership approach to research that ***equitably involves*** community members, organizational representatives, and academic researchers in ***all aspects of the research process.***" Detroit URC

"A ***collaborative*** approach to research that ***equitably involves all partners*** in the research process and recognizes the unique strengths that each brings. CBPR begins with a research ***topic of importance to the community*** and has the aim of combining knowledge with ***action*** and achieving social change..." W K Kellogg Community Health Scholars Program

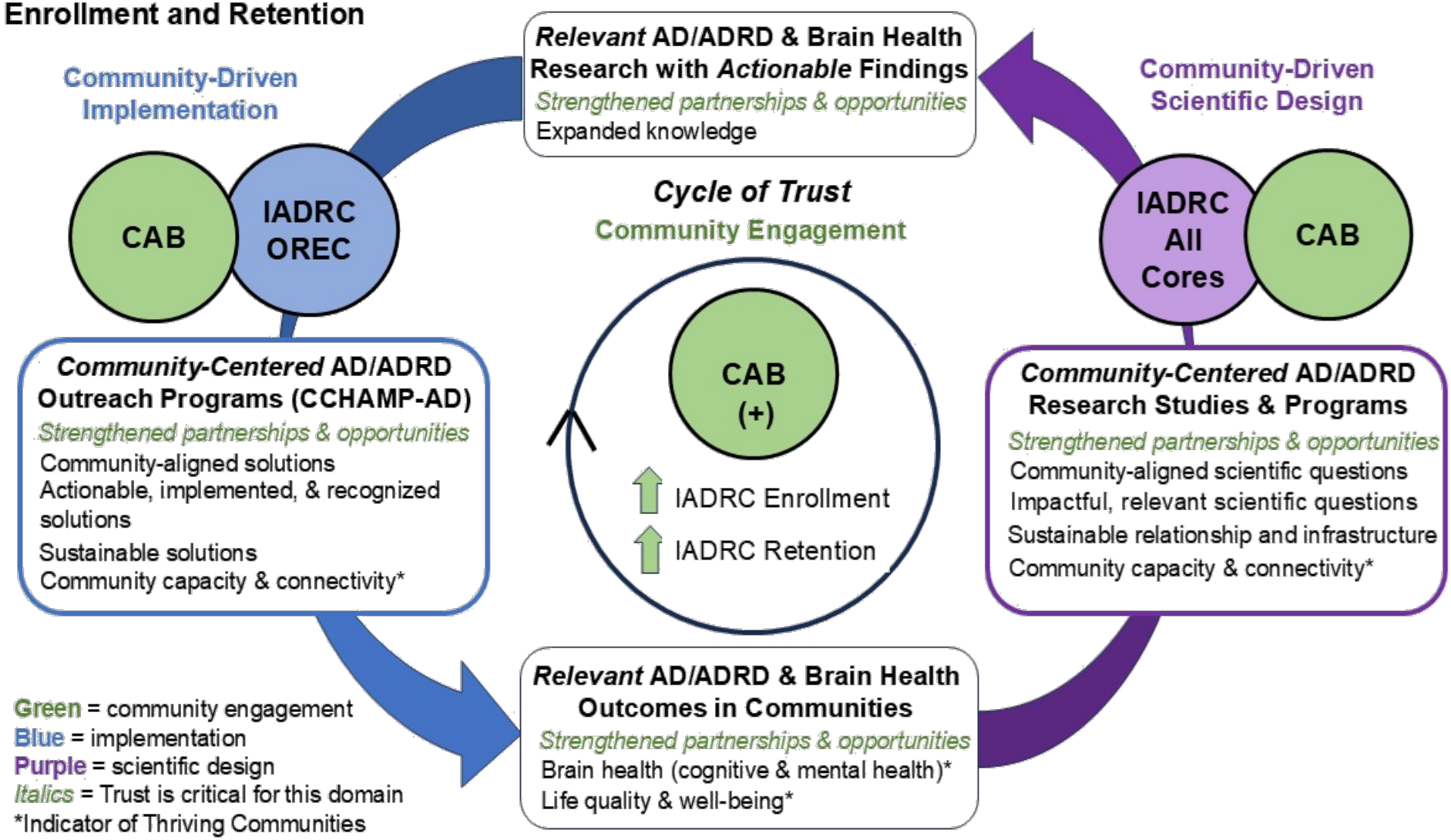
"Answers the call for more ***patient-centered, community-driven research approaches*** to address growing health disparities."

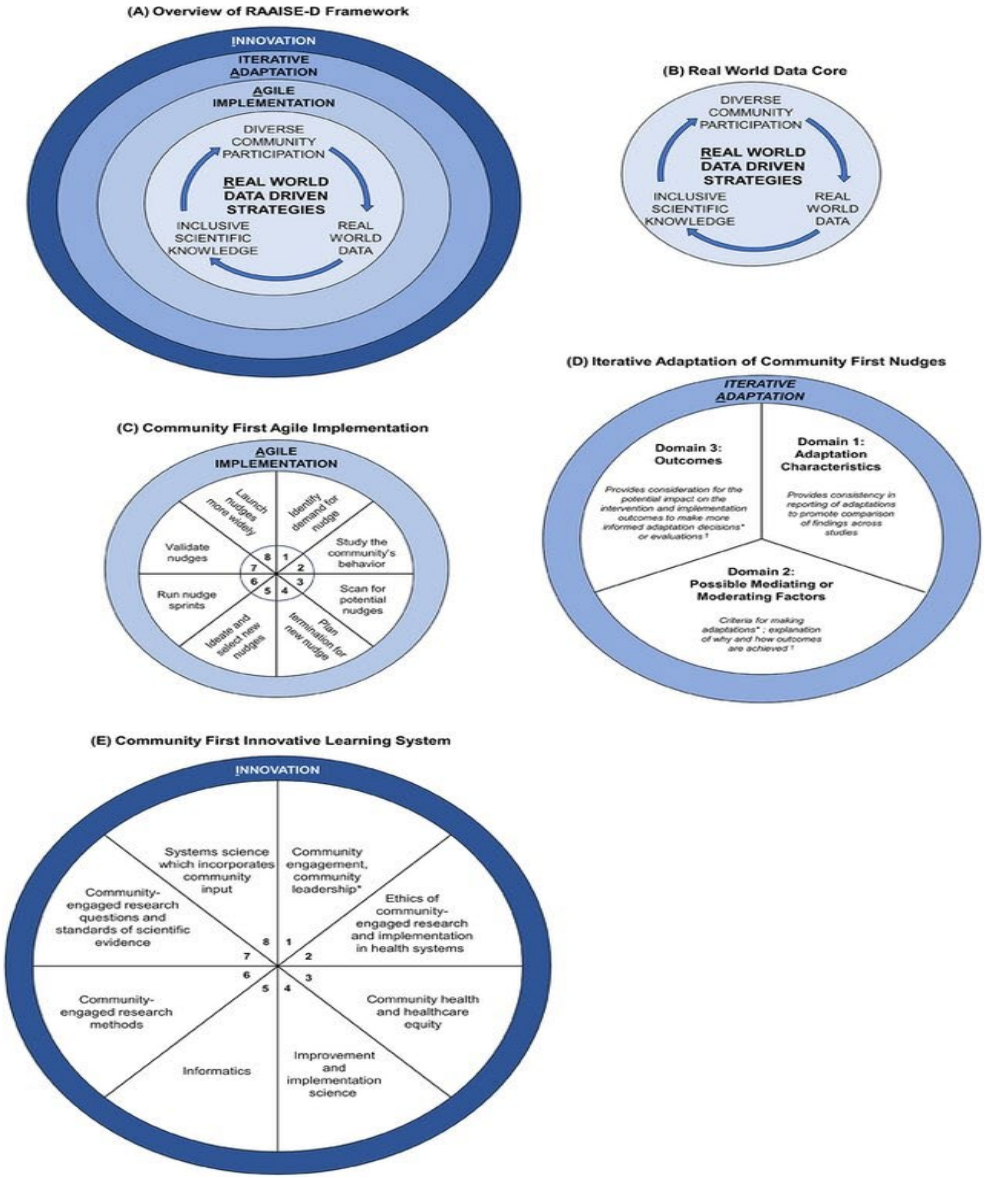
(Collins et al., 2019)

Core Objective Dimension	Researchers' Perspective (Methodological & Institutional)	Community's Perspective (Practical & Empowerment)
Data Quality & Scope	Improved Accuracy & Relevance: Aligns research questions and data collection to enhance baseline validity and target interventions.	Describe Priorities: Provides a platform to explicitly define the true scope of localized health issues.
Institutional Relationships	Building Trust and Equity: Repairs historical power imbalances and establishes institutional rapport with marginalized groups.	Get Contextual Answers: Demands clear answers to highly specific questions affecting service populations.
Intervention Design	Cultural Relevance: Guarantees that active clinical approaches are highly sensitive to community context.	Develop Local Programs: Facilitates the creation and adaptation of culturally appropriate community resources.
Operational Success	Enhanced Implementation: Maximizes retention and recruitment success through therapies co-designed for local infrastructure.	Conduct Evaluations: Equips community entities with the tools to measure the true efficacy of their internal programs.
Long-Term Outcomes	Lasting Impact & Empowerment: Focuses Community-Based Participatory Research (CBPR) on building sustainable local capacity.	Policy Advocacy & Funding: Secures the hard data and personal stories needed to win financial grants or legislative policy shifts.

(Better., 2023; Jack et al, 2014)

Figure 1. Engaging Communities in All Steps of the Research Process Builds Trust and Increases Enrollment and Retention





(A) Overview of RAAISE-D Framework. Real-world agile, adaptive, innovative learning systems to engage diverse communities.
(B) Real World Data Core through the Creation of Real-World Data Driven Strategies through a cycle of diverse community participation in research, which generates real world data, leading to inclusive scientific knowledge.
(C) Eight Steps for Community First Agile Implementation adapted from Agile Implementation Framework
(D) 3 Domains of Iterative adaptation of Community First Nudges.
(E) Community first innovative learning system.

(Richards et al., 2025)

4/1/25 - 3/31/26

- ***Historical Landmarks in cohort URG participation:***
  - ***30.2%*** *Black/African American*
  - ***1.6%*** *Hispanic/Latino*
  - ***11.2%*** *Veteran*
  - ***13.7%*** *≤12 years education*
- *High enrollment in affiliated studies*
- ***10 publications*** *with contributing CAB members*
- *Total Number of IADRC Participants:* ***556****
- *Local-partners collaborations*











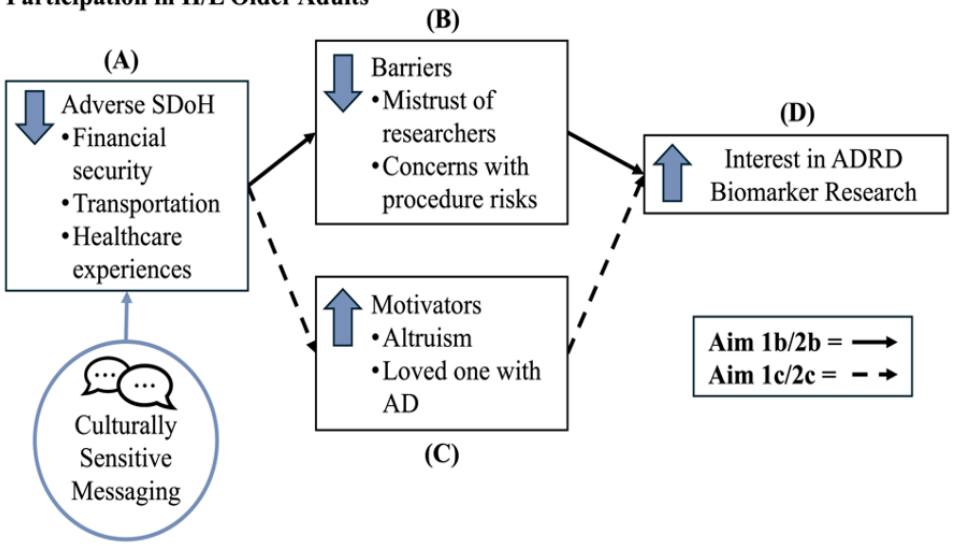


Engaging Hispanic/Latino Older Adults

- *Communication delivered through trusted community sources (e.g., churches, community organizations).*
- *Strong interest in receiving biomarker results with explanations*
- *Interest in educational opportunities following community gatherings (e.g., after Mass, workshops, lectures, discussions, picnics).*
- *Importance of minimizing the collection of identifiable information*

- *Limited understanding of Alzheimer's disease, dementia, biomarkers, and diagnostic pathways.*
- *Frequent confusion between normal aging and ADRD symptoms.*
- *Strong interest in learning more about ADRD, caregiving, and available resources.*

Figure 1. How Culturally Sensitive Messaging Increases Interest in ADRD Research Participation in H/L Older Adults



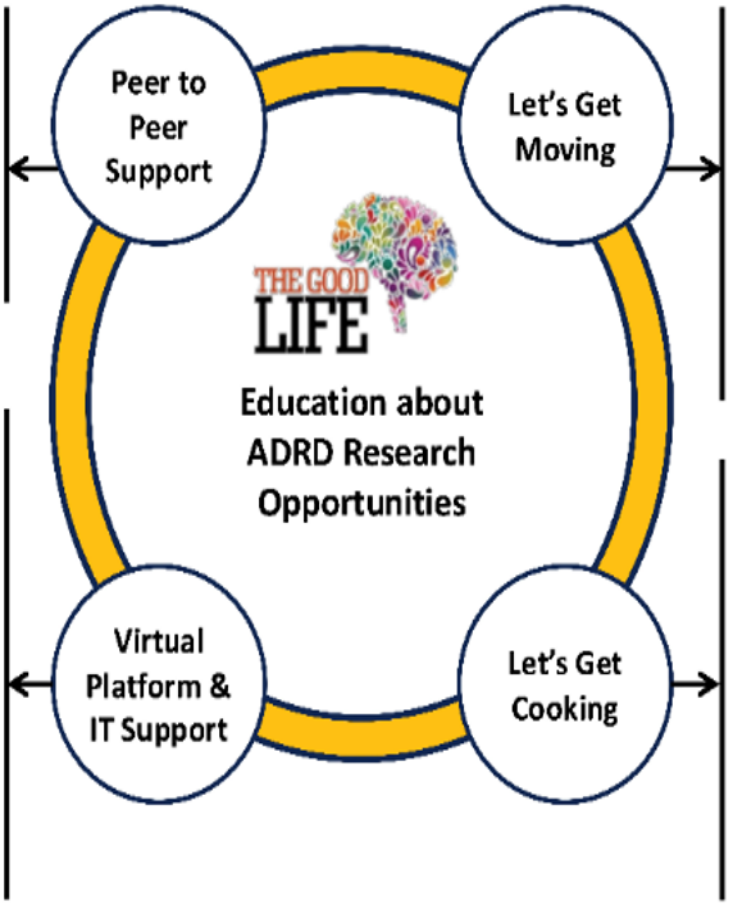
- *Preference for concise, positively framed, and easy-to-understand messaging*
- *Testimonials and community-centered messaging viewed favorably.*
- *Suggested reframing of the IADRC mission to emphasize contributions to local efforts.*

Towards Clinical Trial Readiness

Figure 3. Components of *The Good Life*

- Group therapy-like formatted meeting series
- Promote mindfulness and emotional literacy
- Maintain a schedule of pleasant events

- Interactive delivery of *live* virtual wellness classes
- Online "community" space through social media livestreams
- Advanced ticketing and customer relations management to assist with technology
- "Let's Get Techy" sessions (IT support that helps seniors with their tech questions



- Exercise classes led by a certified fitness trainer
- Uses American College of Sports Medicine's empirically validated *Exercise is Medicine* curriculum
- Workouts tailored for increasing fitness safely and effectively

- Led by staff trained in *18 Reasons* cooking curriculum (empirically validated nutrition program)
- Uses hands-on kitchen training
- Promote caloric restriction and healthier food replacement (CDC's Diabetes Prevention Program)

The Indiana Hub of Collaboration Enables Progress!

National Institute on Aging DESIGNATED Alzheimer's Disease Research Center

SCHOOL OF MEDICINE
CENTER FOR NEURODEGENERATIVE DISORDERS

INDIANA ALZHEIMER'S DISEASE RESEARCH CENTER

SCHOOL OF MEDICINE
STARK NEUROSCIENCES RESEARCH INSTITUTE



CLARiTI
ADRC Consortium for Clarity in ADRD Research Through Imaging

University Center for Neuroimaging CfN

The Neighborhoods Study



NCRAD
National Centralized Repository for Alzheimer's Disease and Related Dementias

OMNI ADRD

MODEL-AD
Model Organism Development & Evaluation for Late-Onset Alzheimer's Disease

SpeechDx
Unlocking Alzheimer's Disease through Voice-Based Biomarkers

ReCARDO
Catalyzing Real-World Data • Accelerating Dementia Research

TREAT-AD
TaRget Enablement to Advance Therapy Development for AD

R24: Collaborative for Aging Research and Engagement (CARE)

ALLFTD
ARTFL LEFFTDS Longitudinal Frontotemporal Lobar Degeneration

ADNI
Alzheimer's Disease Neuroimaging Initiative

Diverse VCID

adsp Alzheimer's Disease Sequencing Project

PHC Phenotype Harmonization Consortium

Alzheimer's Disease Metabolomics Consortium

NIAGADS

GCAD Genome Center for Alzheimer's Disease

LEADS
Longitudinal Early-Onset Alzheimer's Disease Study

Indiana Memory and Aging Study; COVID-19 Studies

ADGC Alzheimer's Disease Genetics Consortium

adsp Alzheimer's Disease Sequencing Project

NIH National Institutes of Health
Center for Alzheimer's and Related Dementias

ALZHEIMER GUT MICROBIOME PROJECT

DIAN
Dominantly Inherited Alzheimer Network

DIAN TU
Dominantly Inherited Alzheimer Network Trials Unit

KBASE
Korean Brain Aging Study for the Early Diagnosis and Prediction of Alzheimer's Disease

AI4AD
GENETICS IMAGING COGNITION TREATMENT

T32 Training Programs

Cryo-EM Studies

CLEAR-AD
Centrally-linked Longitudinal pEripheral biomARkers of Alzheimer's Disease

Levels of Community Engagement

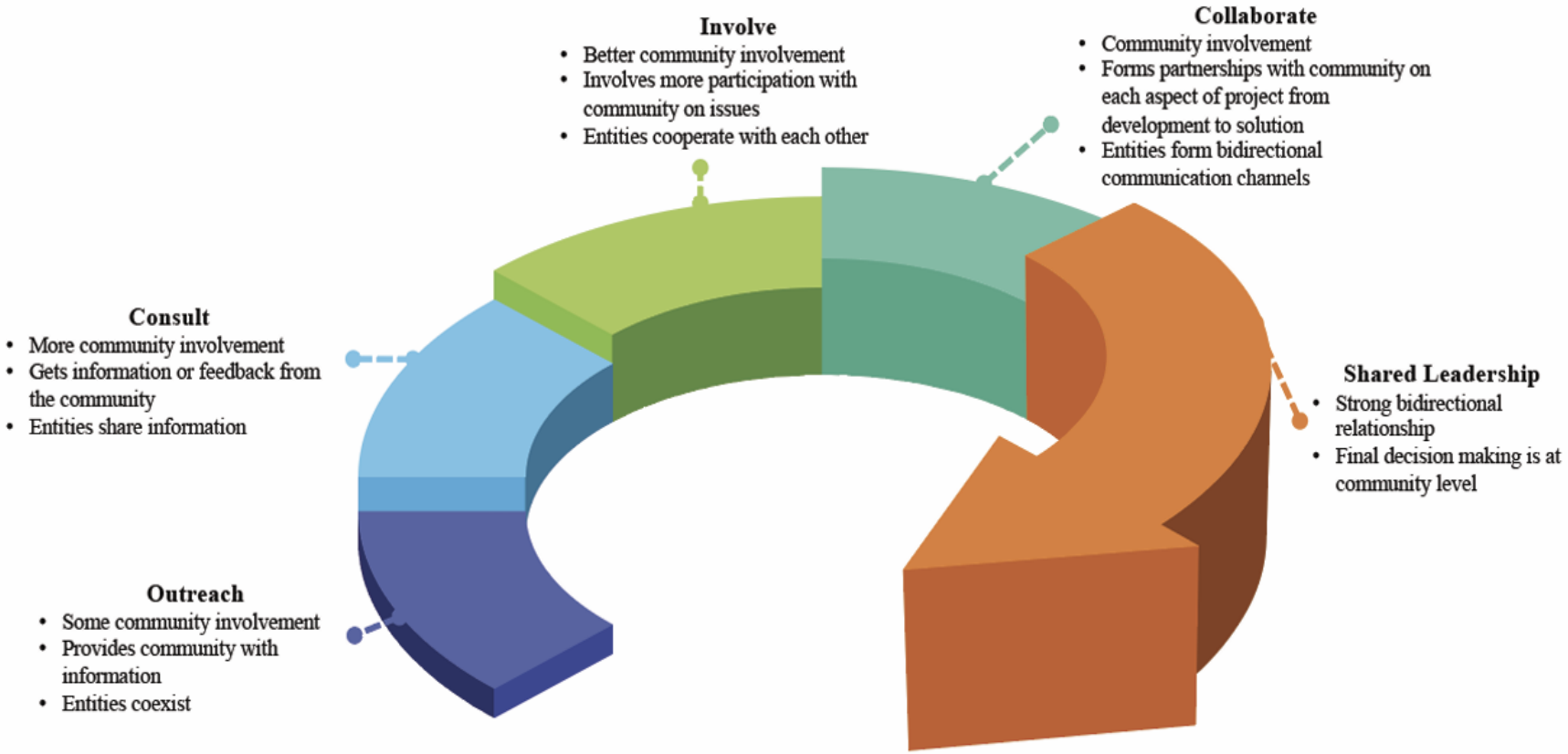


Figure 1 adapted from NIH (2018)

Macro-Level Structural & Social Context

1. Social Determinants (SDoH) as Neurobiological Drivers
2. Geographic Isolation & Multi-Sector Rural Aging

Exposures & Life-Course Experiences

3. Cross-National & Migration Aging Analyses
4. Occupational Wear & Lifespan Weathering

Biological Pathways & Endophenotypes

5. Cerebrovascular Disease & Mixed Pathology
6. Genetic Heterogeneity & (APOE4)

Translational Application

7. Cultural Adaptation of Evidence-Based Interventions

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