



CLARiTI

ADRC Consortium for Clarity in ADRD Research Through Imaging

CLARiTI National Inclusion and Engagement Plan

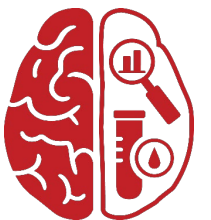
Mónica Rivera Mindt, PhD, ABPP-CN & Ozioma Okonkwo, PhD

Thursday, October 17, 2024



CLARiTI Inclusion Core

- Introduction to Inclusion Core Team and CLARiTI Engagement Goals
- Culturally-Informed Community-Engaged Research (CI-CER) Overview
- CI-CER Approach in CLARiTI
- Next Steps
- Questions/Comments?



CLARiTI Inclusion Core Team



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Inclusion Core Mission

Ensure the inclusion and engagement of persons from Underrepresented Populations (URPs) in CLARiTI by utilizing a culturally-informed community-engaged research (CI-CER) approach, in close coordination with all CLARiTI Cores, esp. the Admin and Return of Results Cores, and with local ORE Cores.

Milestone 1:

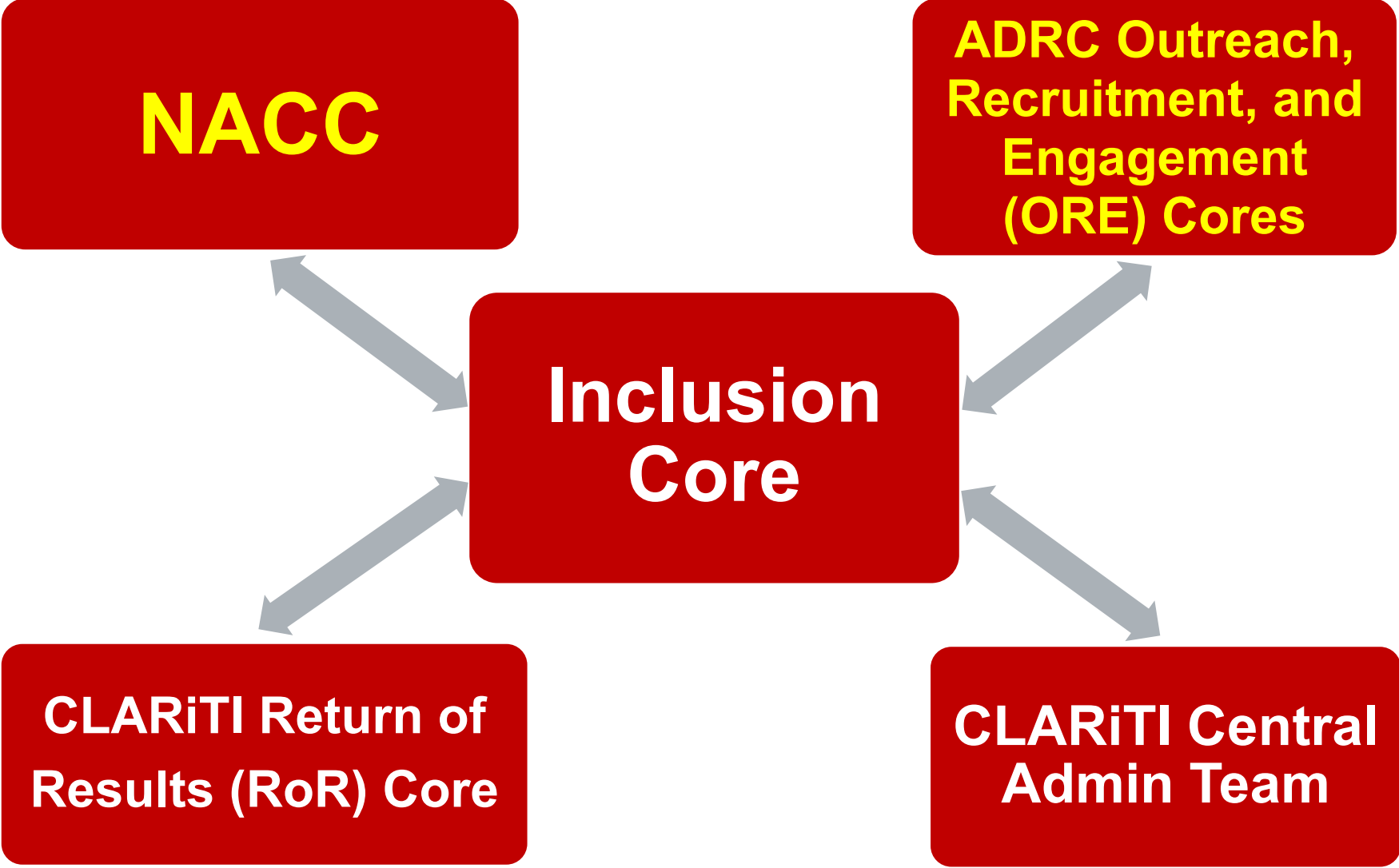
Increase the inclusion & engagement of persons from URPs to $\geq 25\%$ in CLARiTI.

Milestone 2:

Establish and maintain close collaboration and communication with other Cores to meet inclusion goals.



Inclusion Core's *Primary** Partnerships



*But we are happy to collaborate with all Cores, just let us know how we can be of help!

Partnership with ADRC ORE Cores



Success of the CLARiTI Inclusion mandate ($\geq 25\%$ URPs*) requires close collaboration bet. Inclusion Core & ADRC ORE Cores:

- Regular meetings between Inclusion Core (IC) Leadership and ORE Core Steering Leadership
- Regular check-ins between IC Study Team and ORE Core Team Members
- Consultation with ORE Core (*and other Cores*) as needed to support URP inclusion and engagement
- Networking with ORE Core leaders and team members during NACC Directors Meetings!



*URPs: Underrepresented Populations

Inclusion Core Collaboration with NACC

The Inclusion Core thanks NACC for their partnership on two key initiatives:

- **CLARiTI's Public-Facing Website**
 - Connect with public
 - Give back with brain health education
 - Portal for inclusion into CLARiTI
- **'Diversity Dashboard'**
 - Track key inclusion and engagement metrics





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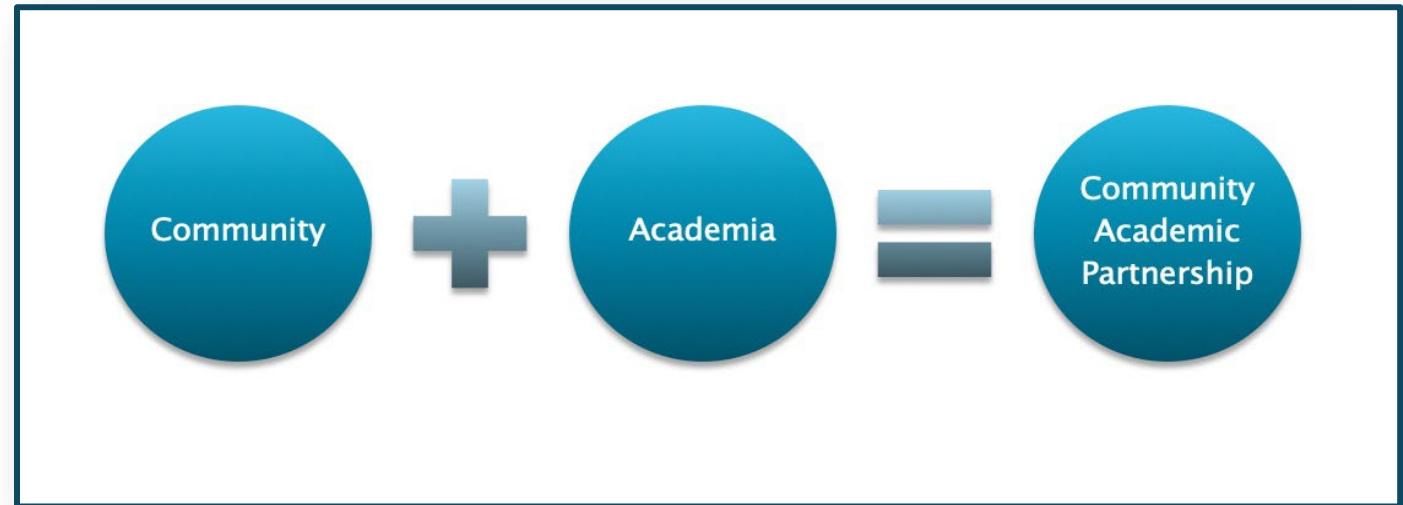
Culturally-Informed Community-Engaged Research (CI-CER): Why?

- **Improves the quality and validity of research** by drawing upon the knowledge and lived experiences of the people involved.
- **Involves communities** that have historically been harmed or excluded.
- **Examines potential harms of research** with the intent to reduce and eliminate it.
- **Acknowledges the effects that research may have on policy.**



CI-CER Key Principles

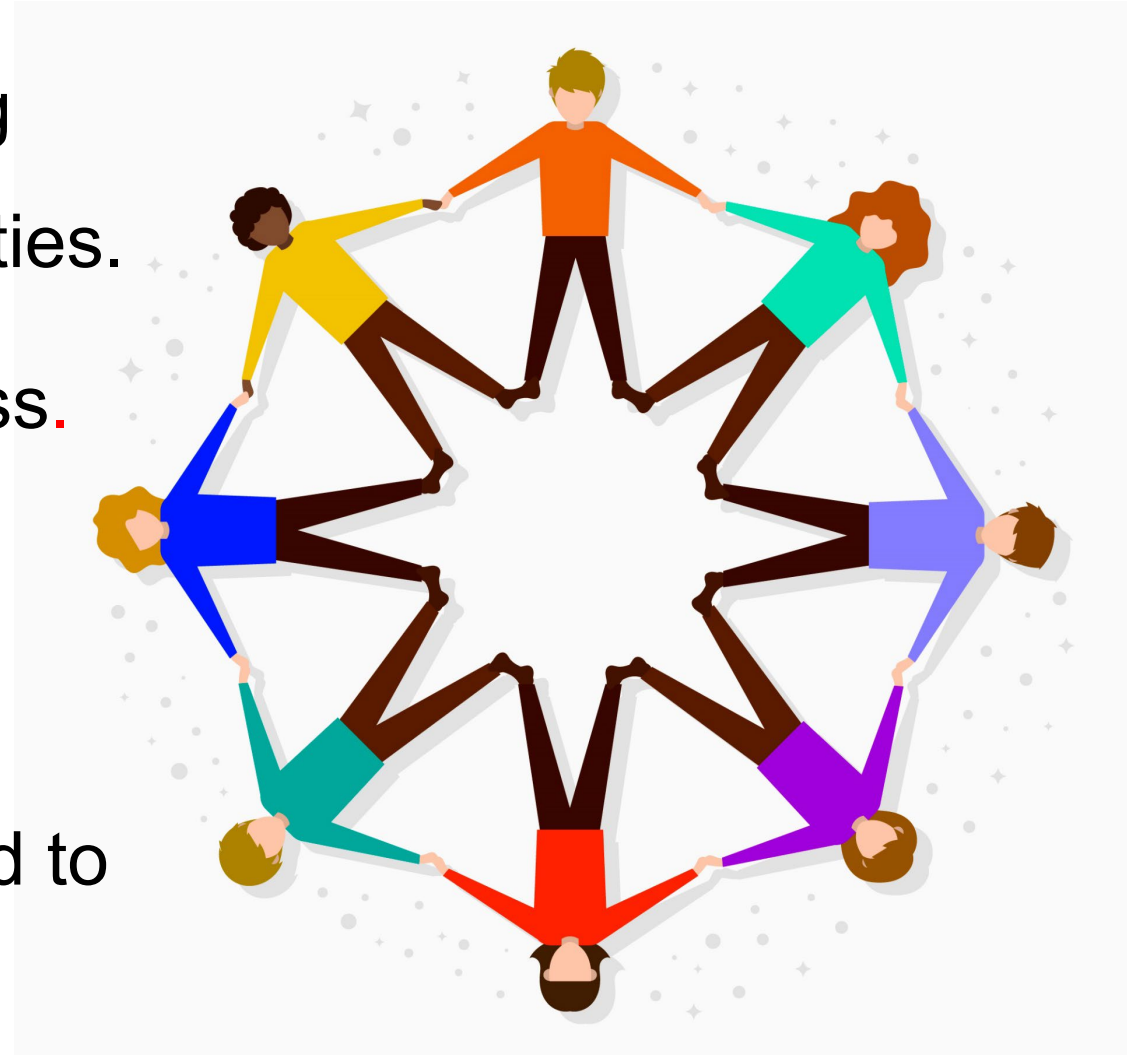
- Recognizes community as a unit of identity.
- Builds on the strengths and resources of the community.
- Facilitates collaborative partnerships in all phases of research.
- Integrates knowledge and action for mutual benefit of all partners.



- Sweat equity, time, credibility, trust
- Meaningful URP inclusion, engagement, and characterization
- Institutional support of faculty/investigators/team members

CI-CER Key Principles, Continued

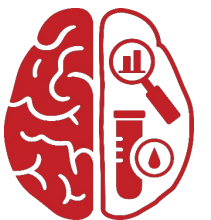
- Promotes a co-learning & empowering process that attends to social inequalities.
- Involves a cyclical and iterative process.
- Addresses health from positive and ecological perspectives.
- Shares findings and knowledge gained to all partners.



Why is CI-CER Important for AD Research?

Impact of CI-CER in AD research

- ADNI3 Diversity Taskforce found “...initial evidence supporting a culturally informed community-engaged approach for increasing inclusion of Black and Latinx older adults in Alzheimer disease cohort studies.”^{1,2}
- A systematic review of AD studies offered some support for improved representation of URPs with community outreach efforts, however, more research is needed.³
- **Takeaway for CLARiTI:** CI-CER approach is an important evidence-based approach for URP inclusion, though more study is needed to inform best practices.



¹Okonkwo*, Rivera Mindt*, Ashford* et al., 2024 (*Co-First Authors)

²Rivera Mindt et al., 2024

³Gilmore-Bykovskyi et al., 2019



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CI-CER Approach in CLARiTI

- **Guidance from the Community-Science Partnership Board (CSPB)**
- **Culturally Competent Research Team**
 - Community Research Liaisons (CRLs)
 - Community Research Navigators (CRNs)
- **Culturally-Informed Outreach Materials**
- **Community Outreach Funds**
- **Ongoing CI-CER Support for Sites**



Community-Science Partnership Board (CSPB)

- **Goal**: To work together in partnership as scientists and community members, to develop strategies, based on the preferences, priorities and voices of community members with cultural humility at the forefront of decision making.
- **CLARiTI CSPB**
 - 12 members: Community members + scientists
 - Meets quarterly
- **First meeting was held 9/9/24!**



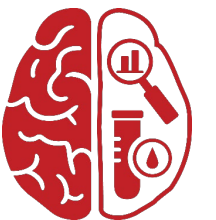
Community Research Liaisons (CRLs)

- **Boots on the Ground:** CRLs provide in-person engagement.
- **“Study Buddy”:** Support URP visits; meet participants “at the curb” to welcome them to the study and help them navigate study visits.
- **The Give:** Work centered on the “give” to community members & organizations.
- **Promote *Inclusion*:** Support community partnerships & liaise with community clinicians, community-based organizations (CBOs), and community members.
- **Coordinate:** Local inclusion/engagement events/efforts with local ADRC leadership & ORE Core team.
- **Participate** in community events!



Community Research Navigators (CRNs)

- CRNs are a part of Inclusion Core team and will virtually engage with staff at each Center.
- Guide and support the community engagement work of CRLs, based on CI-CER principles.
- Act as a knowledge-sharing resource for CRLs and local center staff.
- Additional roles as determined (in collaboration with your ORE Core).



Culturally-Informed Outreach Materials

- Culturally-informed materials will be produced in collaboration with a Latina-owned marketing agency, including:
 - Facebook (*Meta*) ads.
 - CLARiTI pamphlets and brochures.
- CLARiTI Community Science Partnership Board (CSPB) will review and inform **all** outreach materials.



Community Outreach Funds

- **\$10k/year to support community outreach**
- **Funds can be used for:**
 - Building relationships with local Community-Based Organizations.
 - Community outreach events.
 - Advisory boards/councils- stipends or meeting expenses.
 - Participant appreciation initiatives, swag and gifts.
 - Local printing and advertising expenses.
 - We welcome other uses of this outreach funding!



Ongoing CI-CER Support

- **Bi-annual training webinars** on CI-CER for CLARiTI staff
- **Presentations** at Spring and Fall ADRC meetings
- **Collaboration** with ORE Core Steering Committee
- **Repository** of resources and training materials for enhancing CI-CER practices
- **Certification & ongoing training** on CI-CER methods for CRLs
- **Additional CI-CER support** at the request of Centers

Notes. CI-CER = Culturally Informed Community Engaged Research; CRL = Community Research Liaison





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Next Steps: Inclusion Core Onboarding Calls

- Inclusion Core will hold *brief* onboarding calls with each site within 6 weeks of their CAT Site Initiation Visit.
- **Purpose:** Provide sites with information about Inclusion Core's resources and establish collaborative consultation.
- **Content:** Onboarding calls will discuss:
 - Site inclusion goals
 - Site readiness
 - Inclusion Core's resources and support services
- **Attendees:** Calls will be held with each Site's CLARiTI PI, ORE Core leader, study coordinator, and Community Research Liaison (CRL, if applicable).



Key Take Aways for Moving Forward

- **Sustained community engagement** will be crucial for CLARiTI to meet inclusion and engagement goals.
- **Inclusion Core will work directly with Centers** to support their inclusive outreach and engagement strategies.
- **Outcomes of CRL work will be tracked and engagement metrics disseminated** so that Centers can understand the impact of this work and its potential utility in other projects.





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Thank you!

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¡Muchas Gracias!



Questions or Comments?

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**2024 FALL
ADRC
MEETING**