

BEST PRACTICES: OUTREACH, RECRUITMENT, AND ENGAGEMENT EFFORTS WITH DIVERSE COMMUNITIES

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Rush Alzheimer's Disease Center

2019 ADC ORE Meeting

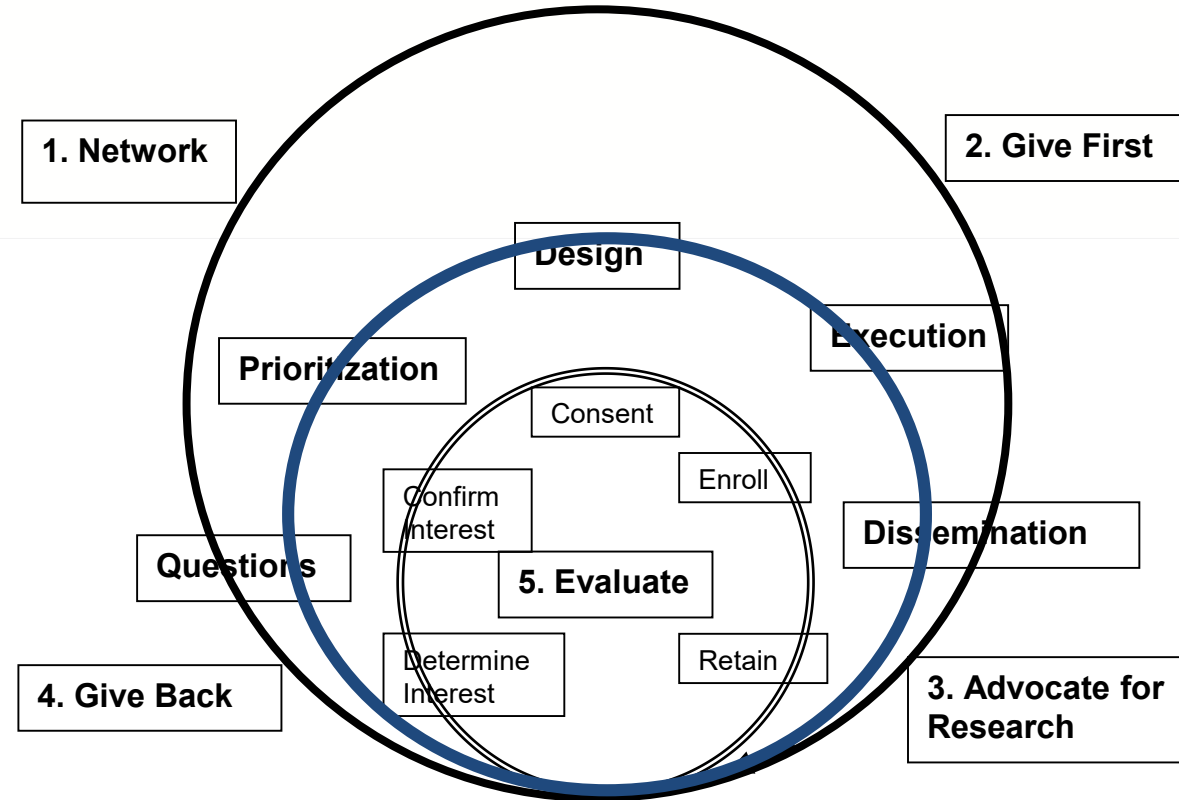
Overall Goal of the RADC ORE CORE

To nurture inclusive and engaged participation of persons traditionally under-represented in research on the etiology, pathogenesis, diagnosis, treatment, and prevention of AD and related conditions.

The NGAGE Model – General Premise

The NGAGE Model

Network
Give First
Advocate for Research
Give Back
Evaluate



Outer circle represents community activities, middle circle represents participant input on research, and inner circle represents individual study activities.

The NGAGE Model – Key Steps and Strategies

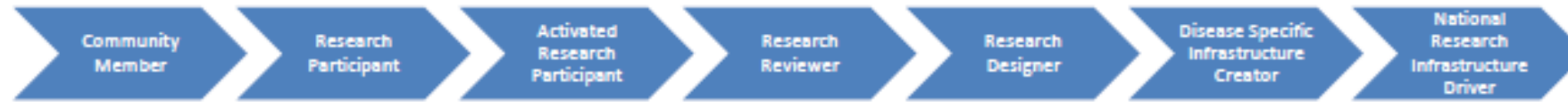
1. Network	<ul style="list-style-type: none">- Build relationships with local leaders, stakeholders, & organizations- One-on-one leader meetings & community board meetings
2. Give First	<ul style="list-style-type: none">- Information transferal- Financial support & sponsorship of activities- Free health fair screenings & encourage memory loss evaluations
3. Advocate for Research	<ul style="list-style-type: none">- Culturally & linguistically congruent materials- Presentations on research participation, AD & cognitive health, biospecimen collection, & brain autopsy- Completion of an Interest Form - interest in or potential commitment to research participation (yes, maybe, no)
4. Give Back	<ul style="list-style-type: none">- Dissemination of research findings- Educational programming focused on prevention, early detection, & early treatment of AD
5. Evaluate	<ul style="list-style-type: none">-Qualitative & quantitative methods-Pre- & post-presentation surveys-Retention events where participants voice concerns re: research participation & related activities through focus groups-Participant feedback regarding best practices for disseminating research findings to communities.

Outreach in Diverse Populations - July 1, 2016 - August 30, 2019

Event or Activity (n=1,460)	# Participants	Race			Ethnicity
		White	Black	Asian	Latino
Network	10,254	59 %	36 %	5 %	34 %
Give First	39,319	54 %	44 %	2 %	32 %
Advocate for Research	5,855	74 %	25 %	1 %	39 %
Give Back	8,690	69 %	27 %	4 %	18 %
TOTAL	64,118	64 %	33 %	3 %	31 %

Higher Order Participation In Research - Premise

Figure 1. The Evolution of Community Member Engagement in Research



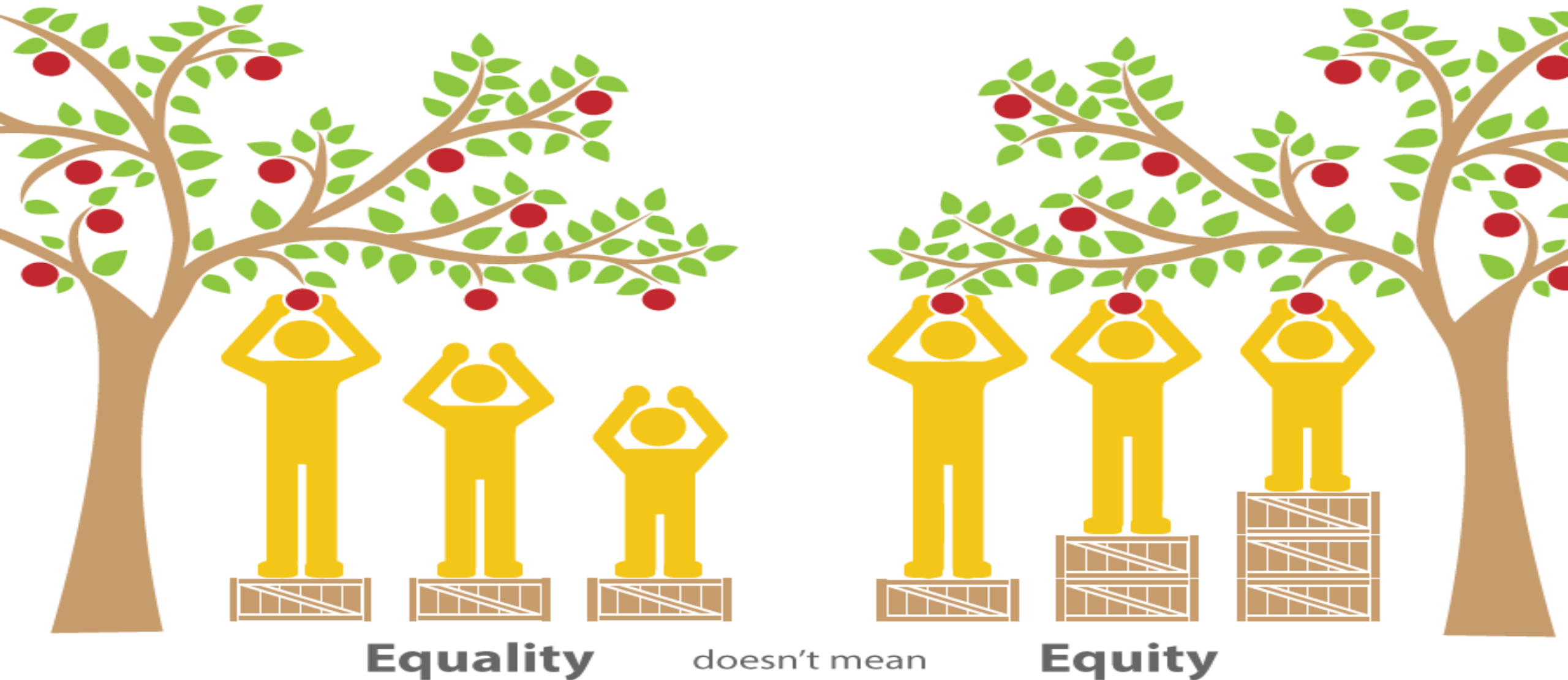
1. **Goal:** Facilitate Center research becoming more engaged and aligned with stakeholders such as participants.
2. **Participant-Centered Research Principles:**
 - A. Have study participant voices heard
 - B. Enable participants to communicate desired health research outcomes
 - C. Empower participants to make informed decisions on research participation
 - D. Participant assessment of the value of health research options
3. **Method Innovation:**
 - A. Introduce complementary qualitative research methodology to the Center
 - B. Facilitate training of researchers on making research participant-centric

Higher-Order Research Involvement Among Diverse Participants

July 1, 2016 - August 30, 2019

		Race				Ethnicity
Participants That:	Total	White	Black	Asian	Other	Latino
Referred another participant	231	79	132	1	19	28
Requested a talk	30	1	23	0	6	6
Shared their story	18	10	5	0	3	9
Assisted with designing a new research proposal	12	6	5	0	1	2
Reviewed a research proposal	8	4	3	0	1	2

In Closing....



Thank You...Questions and Comments

