

The Science of Recruitment in Understudied Populations for Alzheimers Research

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Engagement



EMORY
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**Goizueta Alzheimer's
Disease Research Center**

www.alzheimers.emory.edu

Disclosures

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- Biogen
- Eisai
- Eli Lilly
- Genentech

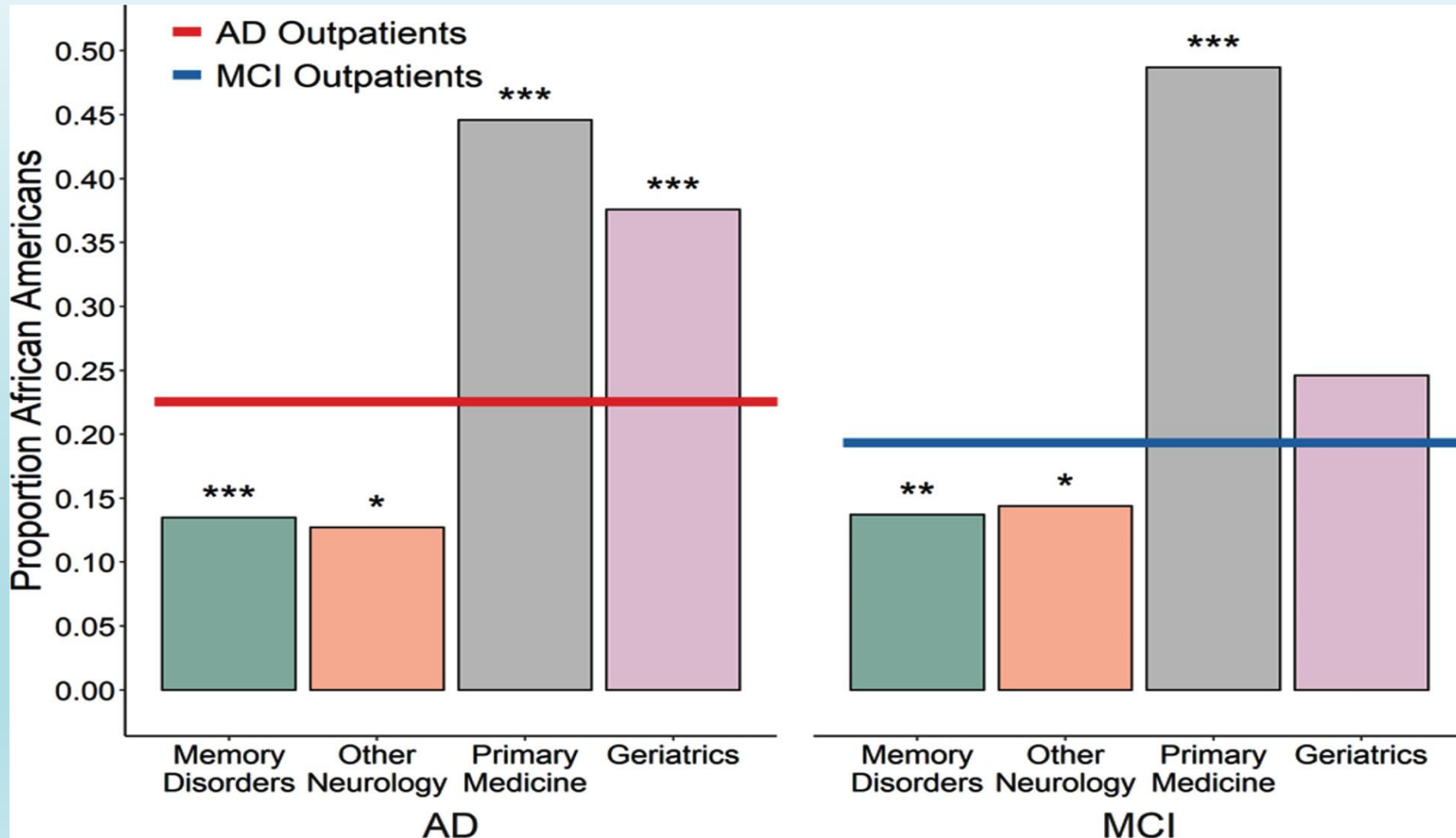
Objectives

- 1) Explain how clinical care access affects ADRD diagnosis
- 2) Illustrate the Georgia State Plan for ADRD Diagnosis
- 3) Define the approach for the participation of Understudied populations in ADRD Research at the Goizueta Alzheimer's Disease Research Center.

Health Equity Snapshot

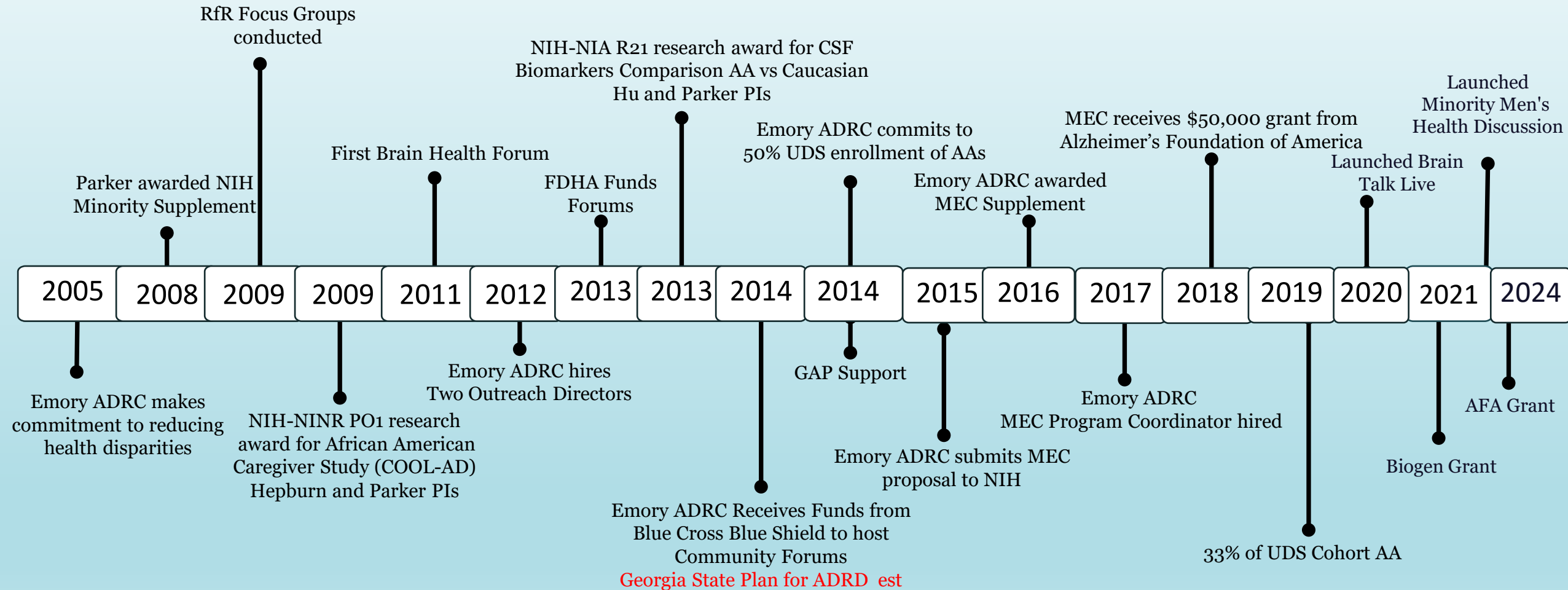
- 1) >50% of the US Residents without health insurance are people of color (DHHS)
- 2) The Life expectancy of Native Americans and Alaska natives is 5.5 year less than all others (Disparities Fact Sheet HIS 2019)
- 3) Cardiovascular Disease comprises 40% of the difference in life expectancy between African Americans and whites (MMWR Surveillance Summaries 2018)
- 4) More than 77% of Latino adults are overweight or obese compared to 67% of white adults (DHHS- Obesity and Hispanic Americans 2020)
- 5) Women have a 9% higher mortality rate post MI or stroke than men (AHA 2016)
- 6) Only 70% of LGBTQ adults seek health care services or have regular access to a regular health provider compared to 90% of heterosexuals (Journal of Clinical Oncology 2020)

Where Do Minorities Seek Medical Care?



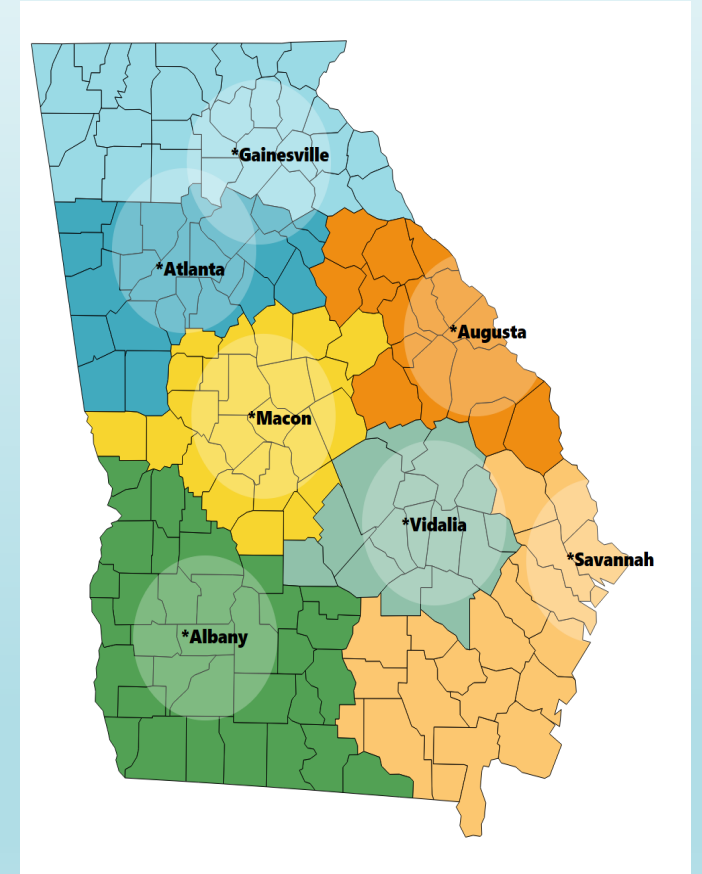
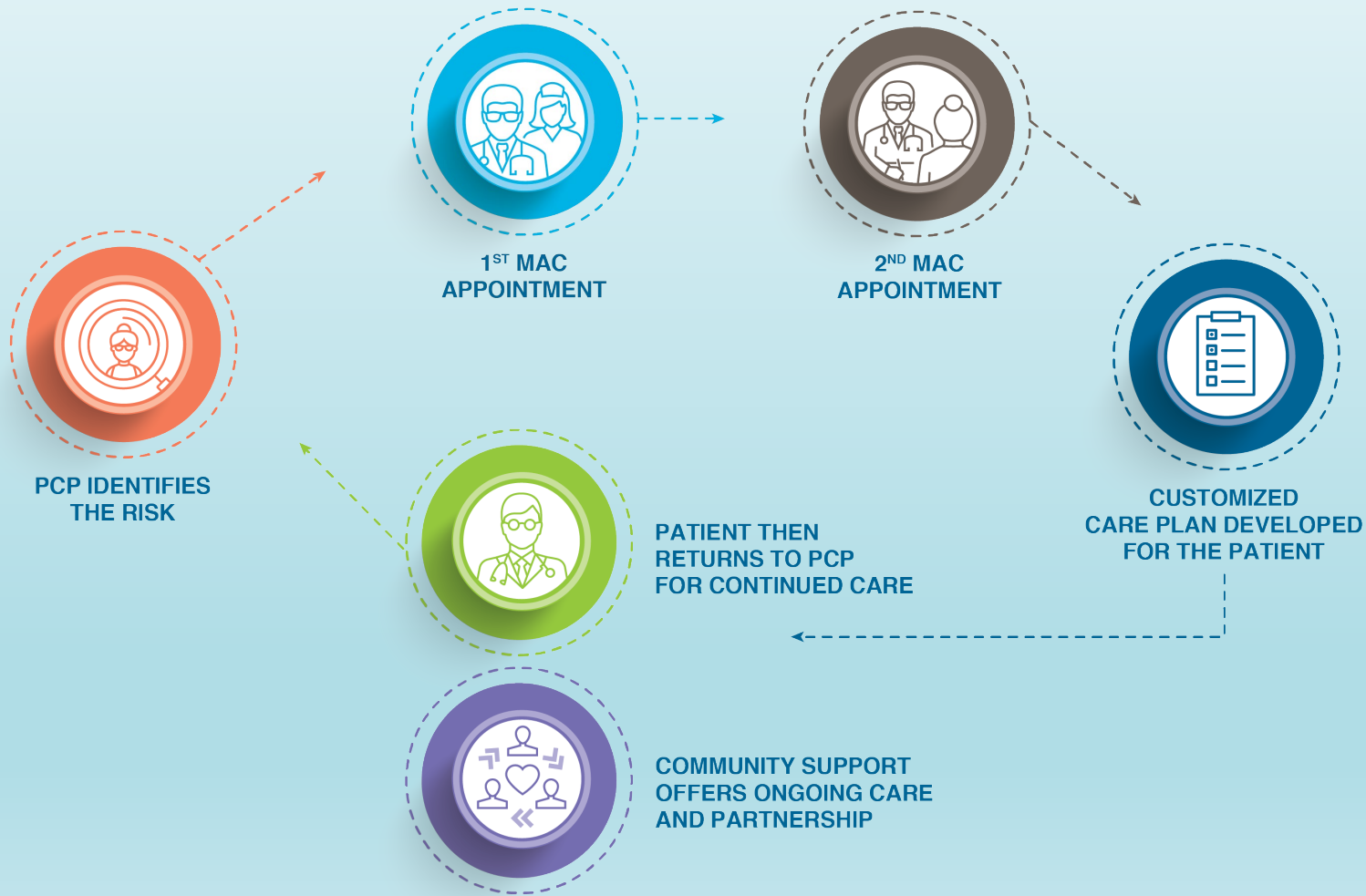
- 188,000 persons with ADRD per Georgia Department of Public Health 2024
- 28.5% of Georgia Population had no doctor or healthcare Access (GA DPH)
- 19% of adults could NOT visit a doctor
- 50% of all Medicare Beneficiaries have multiple chronic diseases
 - *90% of persons with ADRD have multiple Chronic Co-Morbid conditions HTN, T2DM, COPD, CKD*
 - *Persons without ADRD have 1 or fewer chronic comorbid conditions*

Community Engagement Milestones





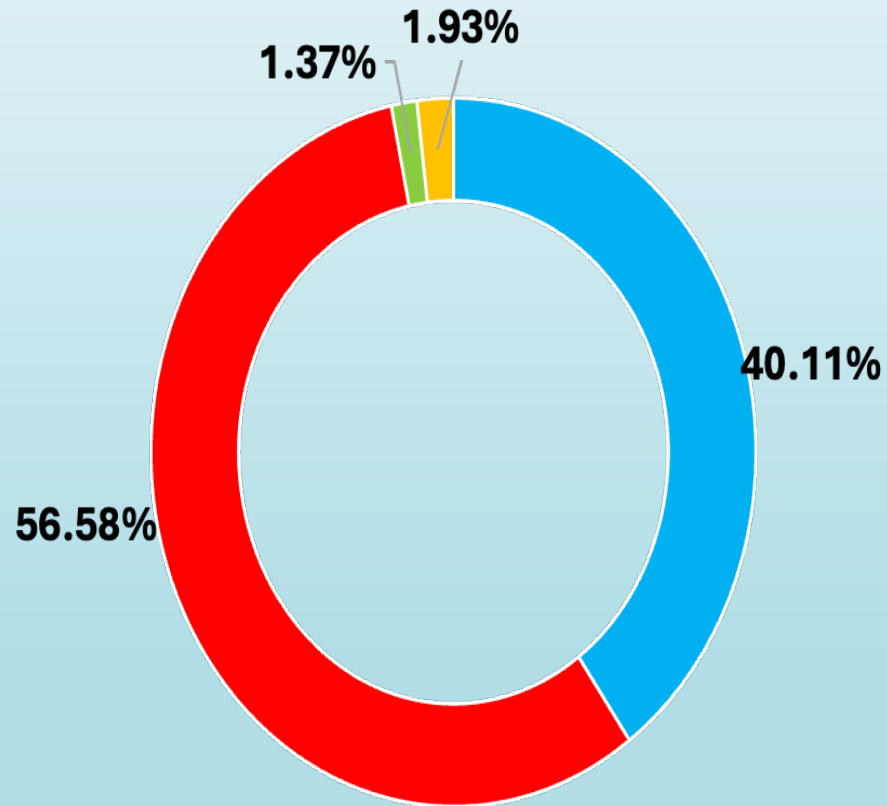
georgia memory net



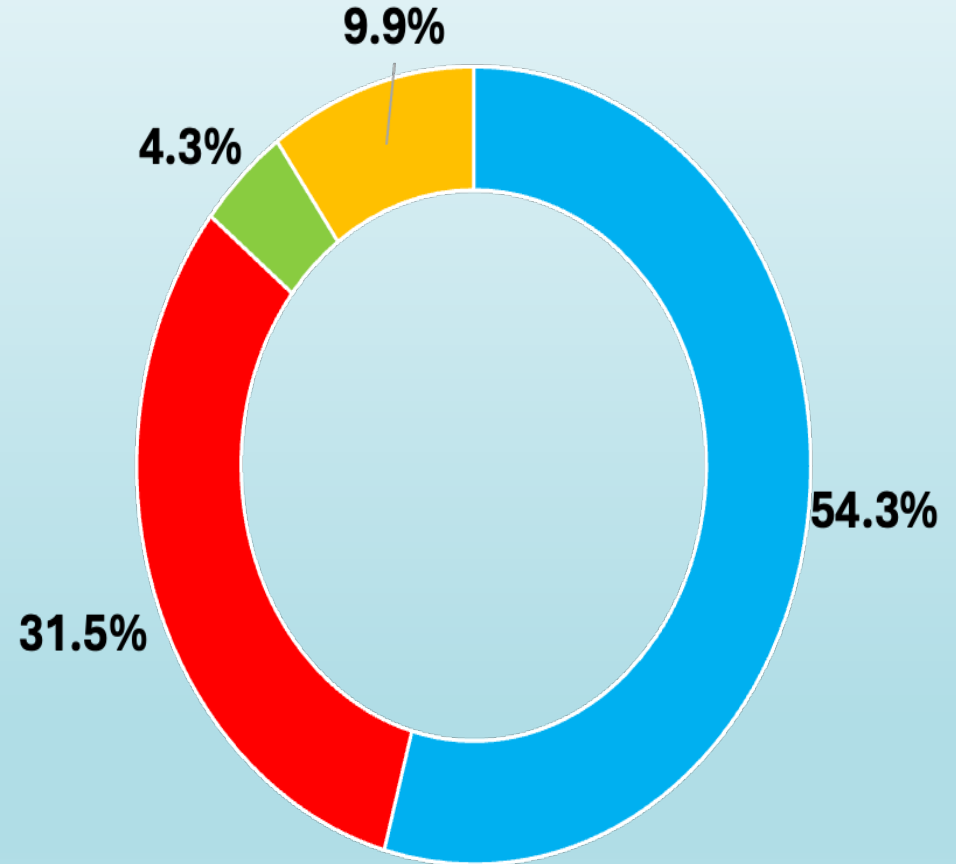


georgia memory net

■ White ■ Black ■ Asian ■ Other
GMN



■ White ■ Black ■ Asian ■ Other
Georgia



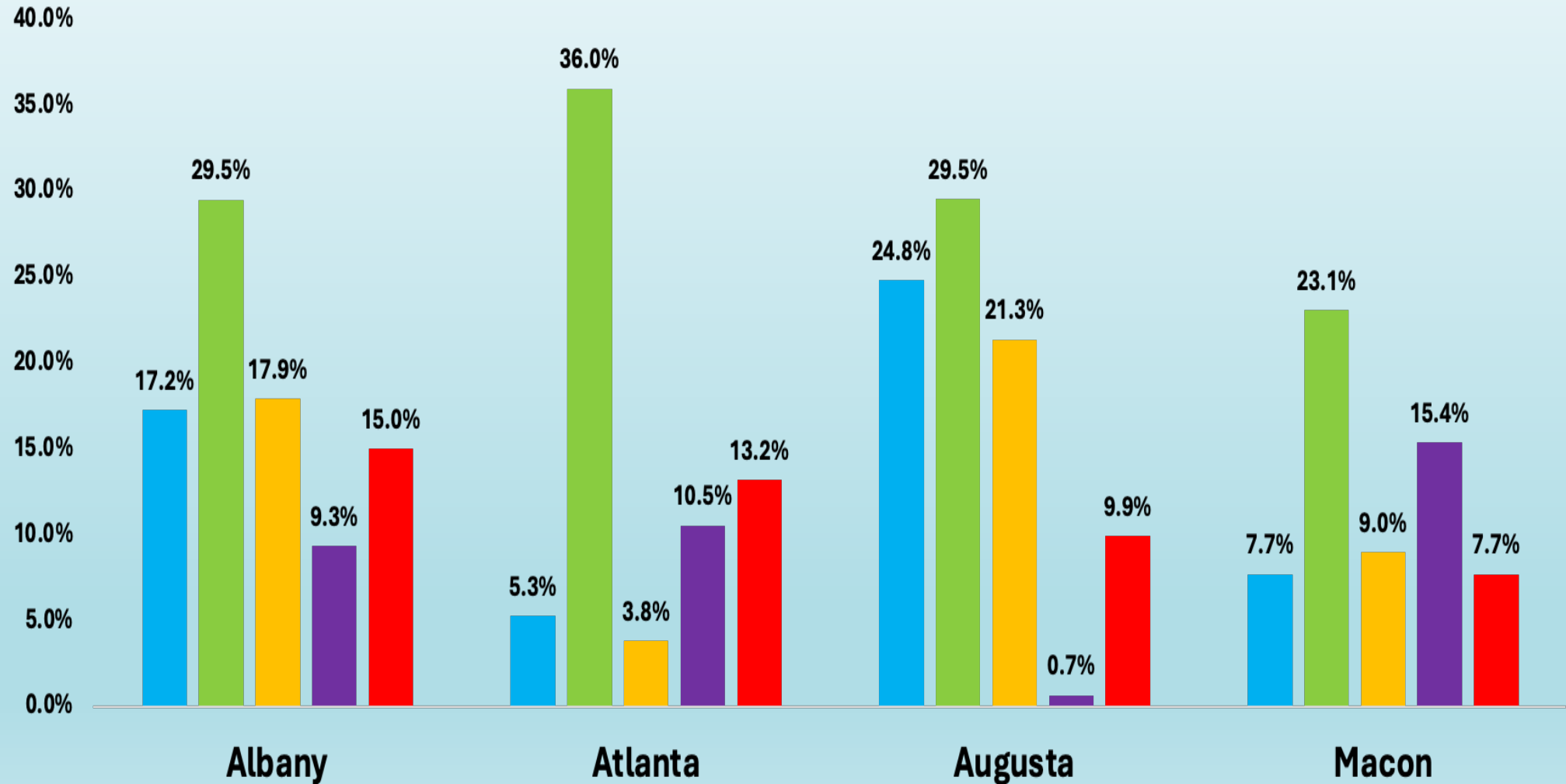
Ethnicity: Only 42 patients (1.9%) of the sample identified as Hispanic/ Latino (Georgia: 10.1%)

Source: U.S. Census Bureau, American Community Survey 5-Year Estimates; 2022



georgia memory net

■ AD ■ MCI ■ Mixed ■ Vascular Dementia ■ Other



To ensure that the discovery and translation of new biomarkers, and pathogenic mechanisms that enable early identification, intervention and treatment of ADRD is applicable to all. All population groups, consistent with their percentage in metropolitan Atlanta, will be represented in clinical research investigation here.

Goizueta ADRC Outreach Approach

1. The recruitment and retention of understudied populations requires intentional, consistent and demonstrable effort.
2. Dedicated personnel must be assigned and focused on recruitment and retention tasks
3. Establish collaborative relationships with organized community groups, serving targeted populations, who have aligned health interests
-e.g. Allied Professionals(MD, RN, LCSW), Non-Profits, Faith-based, Advocacy, Sorority, Fraternity
4. Programming **must** address the health interests, needs and resources of the targeted population.
 - i. Health preservation and healthy aging
 - ii. Patient navigation for healthcare access and care
 - iii. Explanation and clarification of the research “process” and accountability for research activities
5. Educational outreach, specifically tailored for older adults from different cultures and languages, in ongoing health and neurologic research.

A. Weekly Webinar for the Public *Brain Talk Live*

<https://alzheimers.emory.edu/whats-new/brain-talk.html>

National and local physicians and NIH- funded researchers present topics

B. Monthly Minority Mens Health Discussion Group

Physicians and businessmen engage in key discussions for health and well being
Research Recruitment

C. Semi- Annual Brain Health Forum panel Carter Library

D. Community collaborations monthly – Service organizations, churches, civic groups

E. **Arts Engagement-** Atlanta Symphony Orchestra, Outfront Theatre

BRAINTALK LIVE



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**EVERY TUESDAY AT
2:00 ET**

Sign up or access your Zoom
account to register for the webinar:

bit.ly/49hRi7N

Meeting ID: 825 1662 3594

Audio Only: Dial 1-929-205-6099

Join us each week to learn
about ongoing studies and to
hear from various experts on
how to manage, preserve, and
improve your brain health.



Have a question? Call (470) 586-4227
or email mkhart@emory.edu.



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27thbrainhealthforum.eventbrite.com

27th Brain Health Forum



Tuesday, October 22, 2024

Doors open at 10:00 am
Program begins at 10:30 am



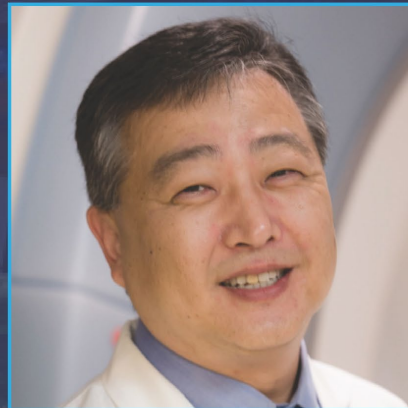
The Carter Center

453 John Lewis Freedom Pkwy NE
Atlanta, GA 30307 Atlanta, GA 30307

Featured Speakers



Monica Parker, MD
Dementia 101



James Lah, MD, PhD
Research Update



Anke Huels, PhD, MSc
Air Pollution and Aging



Andrew Breithaupt, MD
Cognitive Health and AI



Ambar Kulshreshtha, MD
Heart-Brain Connection



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Goizueta Alzheimer's
Disease Research Center

28th Brain Health Forum

Tuesday, April 29, 2025

10:00 AM

Register Today!



4/7/2025

CONFIDENTIAL AND PROPRIETARY INFORMATION



Engagement Activities

Table 2. Significant activities per participant

	Significant activities: median (IQR)	Significant activities: min-max	P-value
Sex			0.54
Female (n=114)	1 (0 – 3)	0-11	
Male (n=78)	1 (0 – 3)	0-19	
Race			<0.0001
AA (n=104)	2 (1 – 4)	0-19	
NHW (n=88)	0 (0 – 2)	0-11	
Sex/race			<0.0001
AA female (n=65) ^{a,b}	2 (1 – 4)	0-11	
AA male (n=39) ^c	2 (1 – 4)	0-19	
NHW female (n=49) ^{b,c}	0 (0 – 1)	0-11	
NHW male (n=39) ^a	1 (0 – 2)	0-8	

Superscripts indicate significant pairwise comparisons:

^aAA female vs. NHW male, p=0.03

^bAA female vs. NHW female, p<.0001

^cAA male vs. NHW female, p=0.0002

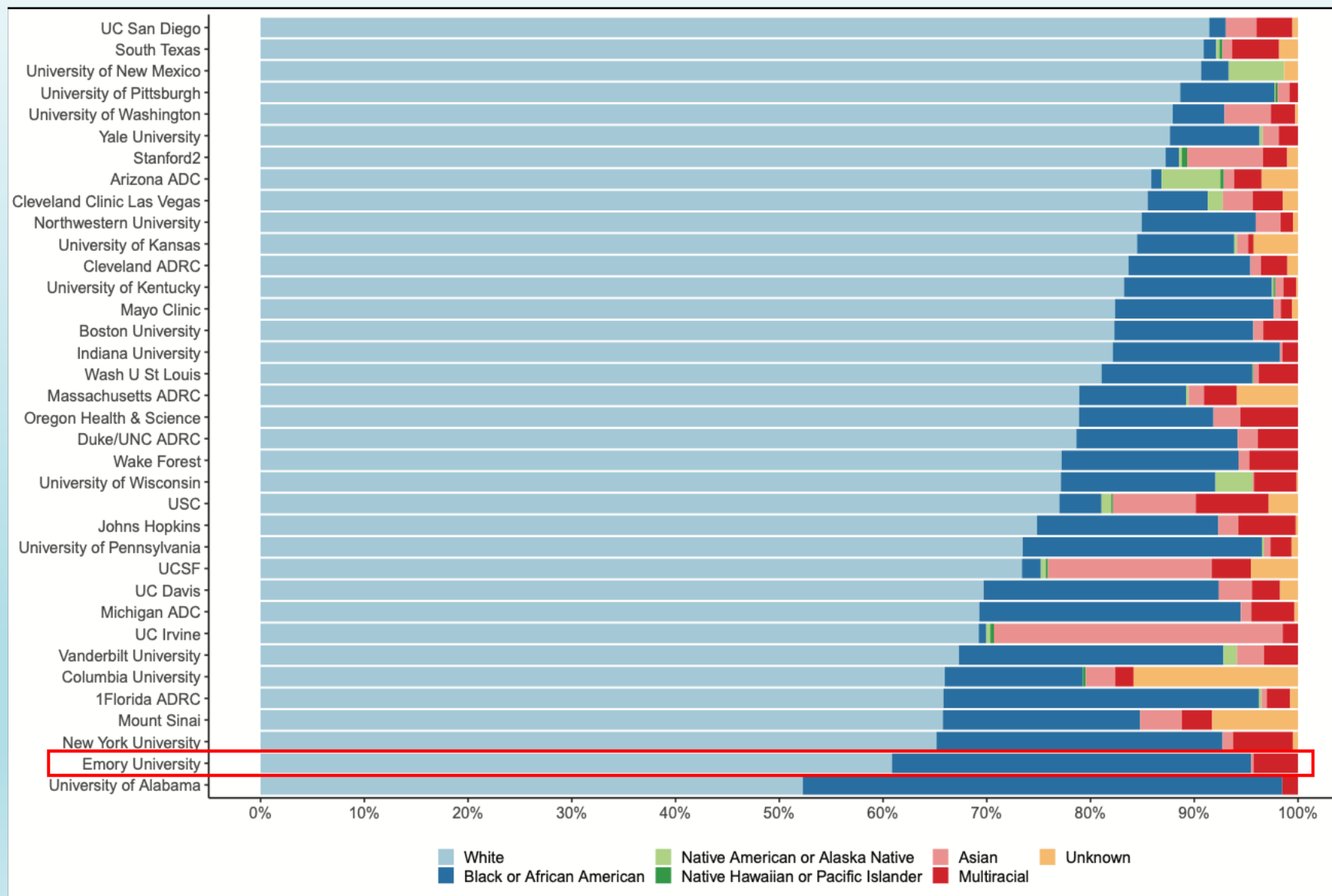
Participant Characteristics TABLES

Table 1. Participant characteristics				
	Full Sample (n=194)	AA (n=104)	NHW (n=88)	P-value
Age, mean (SD)	74.7 (9.1)	74.1 (8.1)	75.2 (9.1)	0.39
Sex				
Female, n (%)	114 (59)	65 (63)	49 (56)	0.34
Male, n (%)	80 (41)	39 (38)	39 (44)	
Education, median (IQR)	16 (14-18)	16 (14-18)	16 (15-18)	0.20
Significant activity count, median (IQR)	1 (0-2)	2 (1-4)	0 (0-2)	<0.0001
First contact to enrollment, days, median (IQR)	-	362.9 (105.3-977.4)	1086.6 (421.6-1586.3)	0.002
Final sample, n=192, excludes 2 self-reported Asian participants				
AA: African American, NHW: non-Hispanic White				

Outcomes

- A) New UDS Cohort enrollees are 50% AA. Center funding 2020-2025 was granted with AA recruitment emphasis as key role for MEC
- B) African American Autopsy rates for UDS participants is 63% (67% all participants)
- C) AA UDS participants are contributing CSF, MRI, saliva, and other biospecimens to support proteomics and novel biomarker discoveries
- D) AA participant biospecimens support multi-center trials focused on AA CSF-RO1 Washington University and University of Pennsylvania; Geocoding-University of Wisconsin
- E) To maintain community trust, establish consistent and transparent relationships that are continuously nurtured in AA and other understudied communities to enable the successful recruitment of viable research volunteers.
- F) Effective recruitment of AA participants for ADNI exceeded other AA ongoing studies

Distribution by Race of Active Clinical Core Participants (9/2024)



Future Recruitment for Research and Biomarker Collection

1. Leverage the Georgia Memory Net (GMN) for new and existing biomarker specimens and longitudinal research participation
2. CSF and radiologic biomarkers are currently part of the clinical diagnostic process for GMN. Blood Biomarkers are not covered due to cost
3. Educational programming will be made available to all sites using new technology
4. Research participation in ADRC studies will depend on what is most accessible to all centers

Barriers to the participation of understudied persons can be overcome with:

- Intentional sustained relationship development
- address of educational and health resource needs
- Increased Professional referral rates for all patients to specialty and research
- The direct engagement of providers and researchers with community