# Community Engaged Research: Pathway to Reducing Disparities

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### *Steering Committee*
### *NIH Pragmatic Trials Collaboratory*

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# What Can Science Do to Reduce Inequities?

- **Standardized measurement of social and demographic factors that affect health**

- **Facilitate discovery science with big data**

- **Be an engine for promoting diversity of the scientific and clinical workforce**

- **Cultivate community engagement and build trust for sustainable relationships**

- **Implement what we know can work to promote health equity**

# Populations with Health Disparities

- Racial and ethnic minority populations in census
- Less privileged socio-economic status
- Underserved rural residents
- Sexual and gender minorities
- Social disadvantage that results in part from being subject to discrimination or racism, and being underserved in health care
- A health outcome that is worse in these populations *compared to a reference population group* defines a health disparity
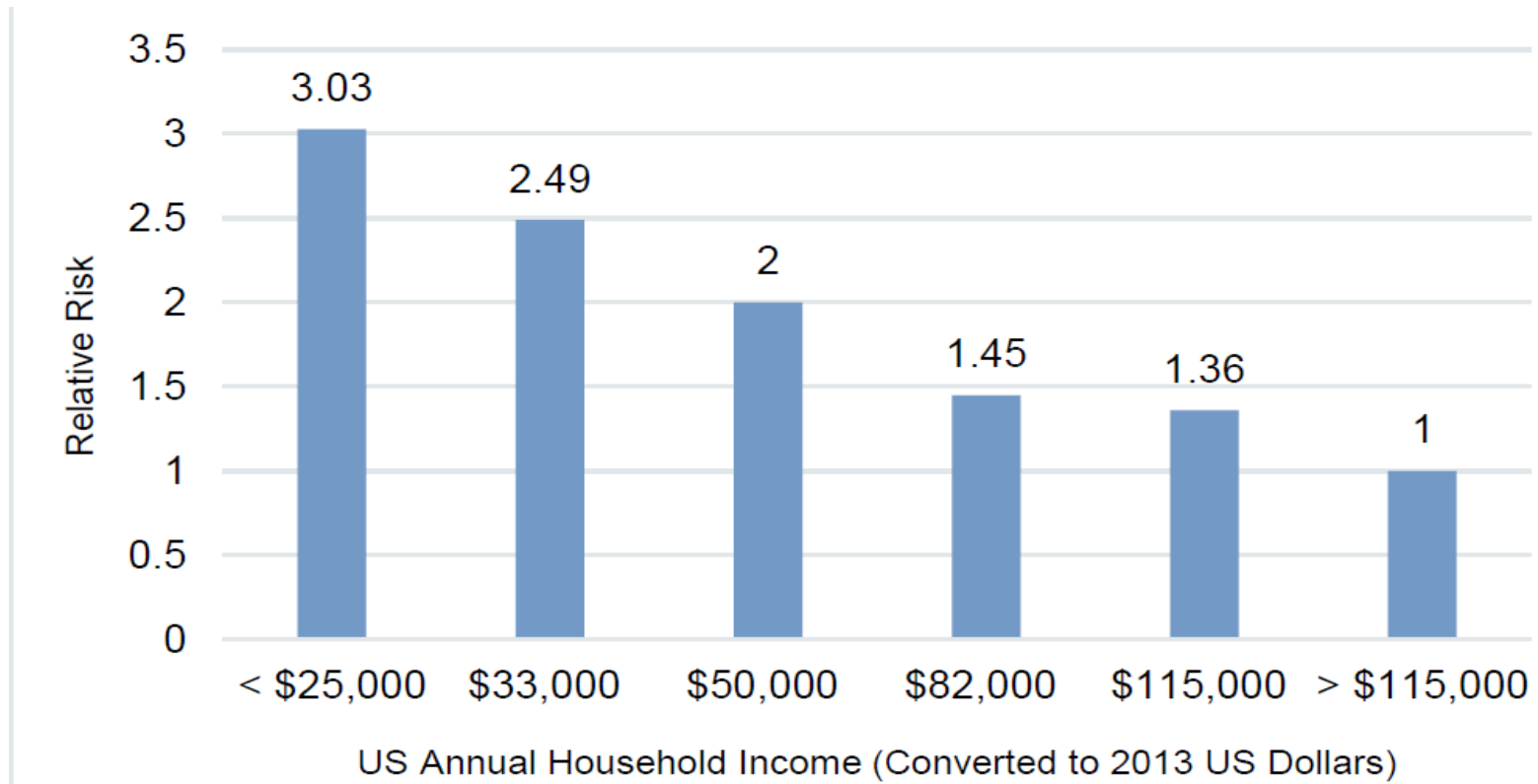
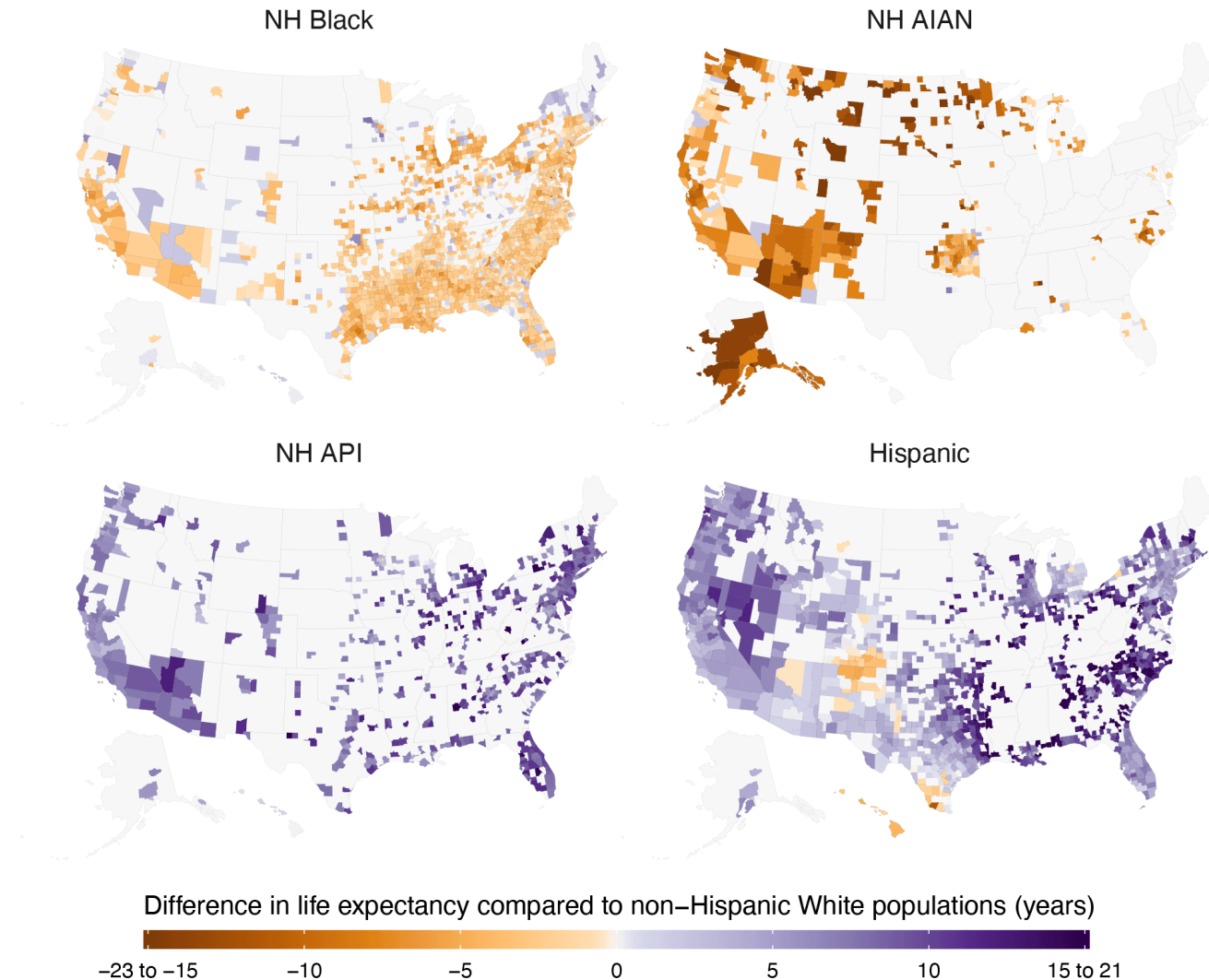# Race/Ethnicity and Socioeconomic Status are Fundamental in Determining Health

- Race/ethnicity and SES predict life expectancy and mortality that are not fully explained

- African Americans have 2X more strokes when compared to Whites for same level of SBP

- Most chronic diseases are more common in persons of less privileged SES

- Among persons with diabetes, all race/ethnic minority populations have less heart disease and more ESRD, compared to White persons

# Relative risk of All-Cause Mortality by US Annual Household Income Level

# Differences in Life Expectancy by County and Race/Ethnicity, US, 2000-2018



NH Black

NH AIAN

NH API

Hispanic

Difference in life expectancy compared to non−Hispanic White populations (years)

−23 to −15    −10    −5    0    5    10    15 to 21

Statistically significant difference (posterior probability > 0.95)

# Rate of COVID-19-Associated Deaths per 100,000 in the US, 2020–2022

| Race and Ethnicity | 2020 | 2021 | 2022 |
|---|---|---|---|
| AI/AN | 190.8 | 201.8 | 86.8 |
| Asian | 67.2 | 66.6 | 34.1 |
| Black | 154.8 | 151.4 | 72.9 |
| NH/PI | 123.5 | 200.9 | 67.8 |
| White | 74.1 | 105.0 | 61.2 |
| Latino | 164.8 | 161.7 | 60.9 |
| Multiracial | 31.9 | 50.7 | 26.7 |

*Deaths per 100,000 (age-adjusted)

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# Social Determinants of Health Measures

- PhenX Toolkit on SDOH measures:
  https://www.phenxtoolkit.org/collections/view/6

- Demographics and individual determinants

- 15 New Structural SDOH Protocols added in December 2022: Affordability accessing dental care and prescriptions, health care communications, internet access, water quality access, neighborhood walking environment, housing instability, minimum wage, residential concentrations of income

- SDOH Core Collection-16 protocols recommended for all

- Individual SDOH-22 protocols and Structural SDOH-15 protocols

# National Institute on Minority Health and Health Disparities Research Framework

| | | Levels of Influence* | | | |
|---|---|---|---|---|---|
| | | **Individual** | **Interpersonal** | **Community** | **Societal** |
| **Domains of Influence** *(Over the Lifecourse)* | **Biological** | Biological Vulnerability and Mechanisms | Caregiver–Child Interaction Family Microbiome | Community Illness Exposure Herd Immunity | Sanitation Immunization Pathogen Exposure |
| | **Behavioral** | Health Behaviors Coping Strategies | Family Functioning School/Work Functioning | Community Functioning | Policies and Laws |
| | **Physical/Built Environment** | Personal Environment | Household Environment School/Work Environment | Community Environment Community Resources | Societal Structure |
| | **Sociocultural Environment** | Sociodemographics Limited English Cultural Identity Response to Discrimination | Social Networks Family/Peer Norms Interpersonal Discrimination | Community Norms Local Structural Discrimination | Social Norms Societal Structural Discrimination |
| | **Health Care System** | Insurance Coverage Health Literacy Treatment Preferences | Patient–Clinician Relationship Medical Decision-Making | Availability of Services Safety Net Services | Quality of Care Health Care Policies |
| **Health Outcomes** | | Individual Health | Family/ Organizational Health | Community Health | Population Health |

National Institute on Minority Health and Health Disparities, 2018
*Health Disparity Populations: Race/Ethnicity, Low SES, Rural, Sexual/Gender Minority
Other Fundamental Characteristics: Sex/Gender, Disability, Geographic Region

# Status of Inclusive Participation in NIH-funded Clinical Research in FY 2022

- **51.5%** of participants are female
- **13%** African American, **12.1%** Latino, **3.4%** Asian, **1%** AI/AN, and **0.3%** Native Hawaiian/Pacific Islander
- 30% minoritized populations – no change since 2016
- **12.2%** unknown –– mostly due to EHR studies
  - Phase 3 Trials – only 8.2% are unknown
- Inclusion across the lifespan with emphasis for persons >80 yr. and children <2 yr.
- System to track inclusion by categories of disease

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# Best Practices for Inclusive Participation in Clinical Studies

- **Recruitment of participants with plan for target sample size to start**

- **Tailor recruitment strategies**

- **Community-engaged approach built on mutual trust — CEAL model**

- **Be intentional in achieving targets by population group**

- **Diverse investigator team**

- **Accountability in publication**

# Inclusive Participation in NIH-Funded Research: Looking Forward

- Mutually exclusive categories by race and ethnicity

- Decrease unknowns to <5% – EHR challenge

- Achieve demographic and meaningful representation

- Support a community-engaged platform to promote participation

- Standardized measure of SES

- Accountability of investigators plans and annual reports

# Challenges to Diversity in Pragmatic Trials

- **Uptake of digital methods to enroll — age, socioeconomic status, English language fluency, males, minoritized populations**

- **Access to a computer and limitations of mobile device data plans**

- **Telemedicine experience — interest is similar, but engagement is lower**

- **Dependence on electronic health record data for demographic factors**

# RADx-UP 138 Awards– Institution Locations

# RADXUP
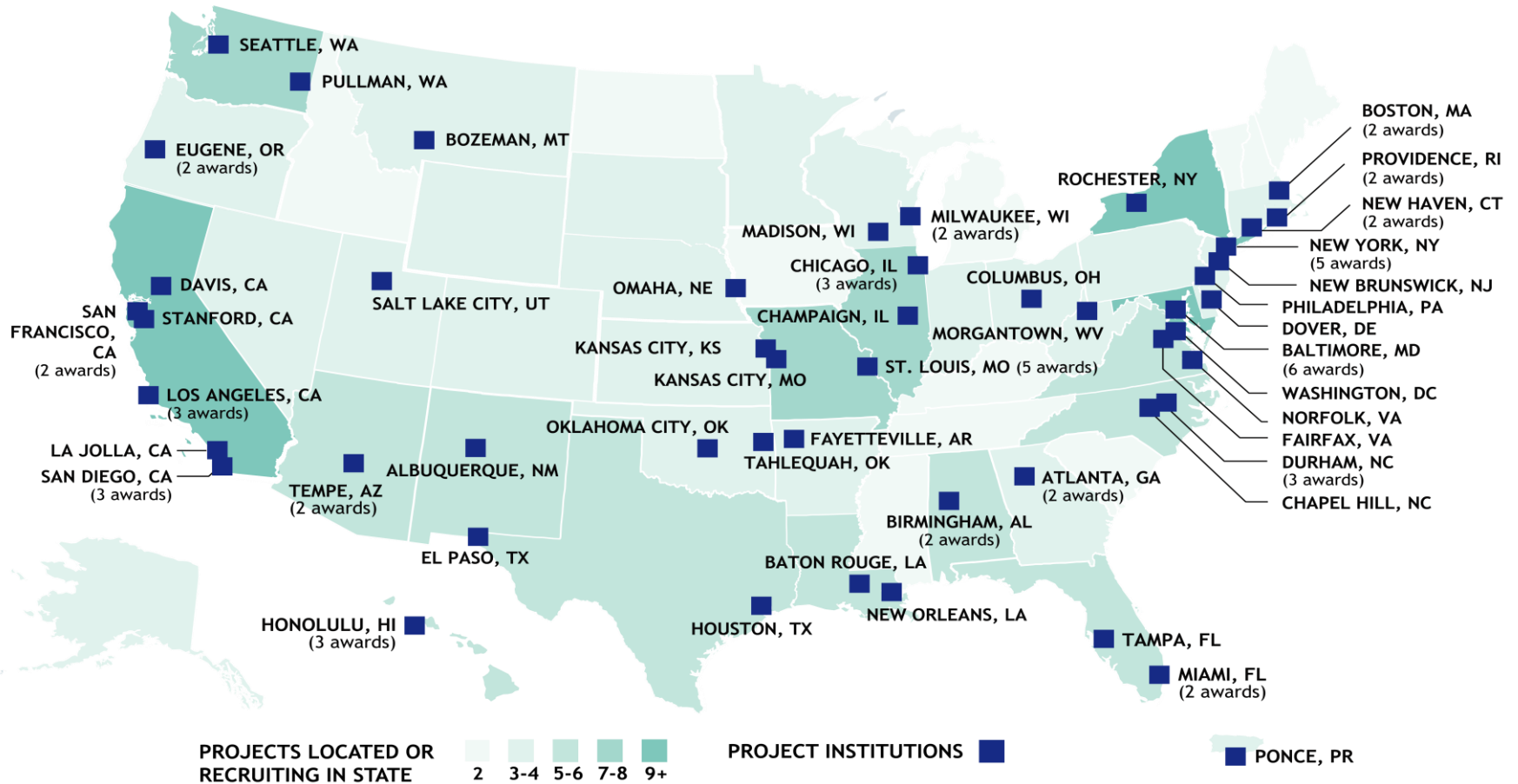
## at a glance

137
COVID-19 testing
and SEBI projects

56
States, territories,
and D.C.

1
Coordination & Data
Collection Center

Data as of 2/1/2023

210
Community-engagement
resources in the RADx-UP library

106
Projects submitting
CDEs to CDCC

>365,500
**Enrolled participants
(prospectively)**

>472,000
COVID-19 tests conducted
(prospectively)

5
Partnering for Impact
writing teams

19
Rapid Research
Pilot Awards

55
Community Collaboration
Mini Grants

167
Published
research articles

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# NIH Community Engagement Alliance (CEAL) Against COVID-19 Disparities

**Expanding the CEAL Alliance**

*CEAL is strategically expanding to focus on urgent community-engaged research and outreach focused on COVID-19 awareness and education among communities hardest hit by the pandemic.*



**2020 Teams**
- Alabama
- Arizona
- California
- Florida
- Georgia
- Louisiana
- Michigan
- Mississippi
- North Carolina
- Tennessee
- Texas
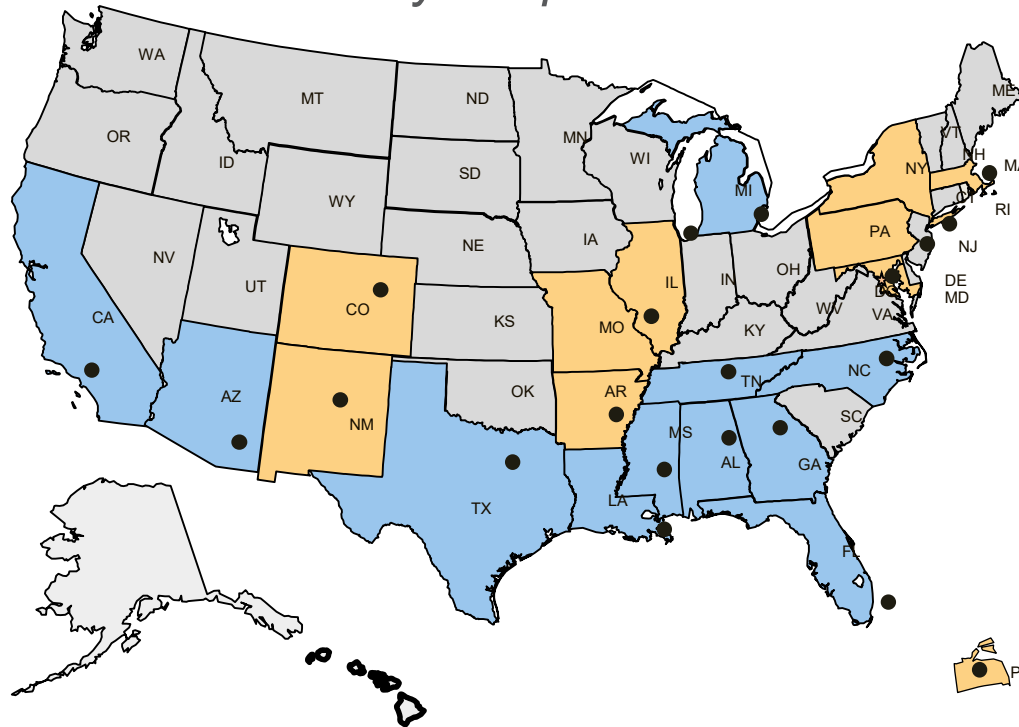
**2021 Awards**
- Arkansas
- Colorado
- DC/MD/VA
- Chicago/IL
- Boston/MA
- St. Louis/MO
- New Mexico
- NYC/New York
- Philadelphia
- Puerto Rico

● Lead P.I. Institution Location

National Institute on Minority Health and Health Disparities

# NIH Community Engagement Alliance (CEAL) Against COVID-19 Disparities

1. Build and sustain **trusting relationships** through **community engagement**

2. **Acknowledge social determinants of health's** role in COVID-19 disparities

3. Move at the speed of **TRUST**

4. Work with **trusted voices** and **trusted messengers** at the national and local levels.

5. **Exhibit agile leadership** and build innovative and strategic **public-private partnerships**



**Community Engagement Alliance (CEAL) Against COVID-19 Disparities**

**In the United States, COVID-19 has taken a greater toll on communities of color.**

CEAL focuses on addressing misinformation around COVID-19, engaging trusted partners and messengers in the delivery of accurate information and educating communities on the importance of inclusion in clinical research to overcome COVID-19, and most importantly, health disparities. This is especially important for people unduly burdened by COVID-19 such as **African Americans, Hispanics/Latinos, and American Indians/Alaska Natives,** who account for over half of all reported cases in the United States.

CEAL's research teams also conduct research on the most effective strategies for ensuring inclusion and for engaging, educating and increasing awareness within these groups about vaccine and treatment clinical trials to prevent and treat the disease.

[COVID19COMMUNITY.NIH.GOV](COVID19COMMUNITY.NIH.GOV)

National Institute on Minority Health and Health Disparities

# Network for Community-Engaged Primary Care Research – NCPCR

- CEAL Initiative funded two sites:

    o Ochin FQHC Network

    o Morehouse School of Medicine + partners

- Initial goals 1) to support clinical research on awareness, education and mistrust related to COVID-19; 2) promote inclusion of populations disproportionately affected by COVID-19

- Underlying goal: Create infrastructure to conduct clinical studies grounded in community-engaged research

# RCMI Clinical Research Network

- **Focus on clinical research studies in settings with established community-engagement**

- **Goal to facilitate research in populations with health disparities and their clinicians**

- **UG2/UG3 Mechanism with two years planning and 5 years to follow; 4 awards made in FY22:**

  o **NC Central**

  o **U Hawaii**

  o **San Diego State**

  o **Meharry**

# Patient-Clinician Communication Matters

- **Linked to higher patient satisfaction, better adherence and improved health outcomes**

- **Race concordant visits for African American patients are longer and more patient-centered**

- **Language concordance = better outcomes**

- **In MEPS, African American and Latino physicians care for >50% of minorities, >70% LEP, and more Medicaid/uninsured patients**

- **In 2020, only 14% of medical school graduates and 12% of practicing physicians were URM**

# Perception of Unfair Treatment: 2015

**In past 30 days, were you treated unfairly because of racial or ethnic background in store, work, entertainment place, dealing with police, or getting healthcare?**

|  | Percent Agree | |
|---|---|---|
|  | **All** | **Health** |
| **Latinos** | **36%** | **14%** |
| **African Americans** | **53%** | **12%** |
| **Whites** | **15%** | **5%** |

*Trust in clinician/institution? Role of Unconscious Bias?*

*Kaiser Family Foundation Survey of Americans on Race, November 2015.*

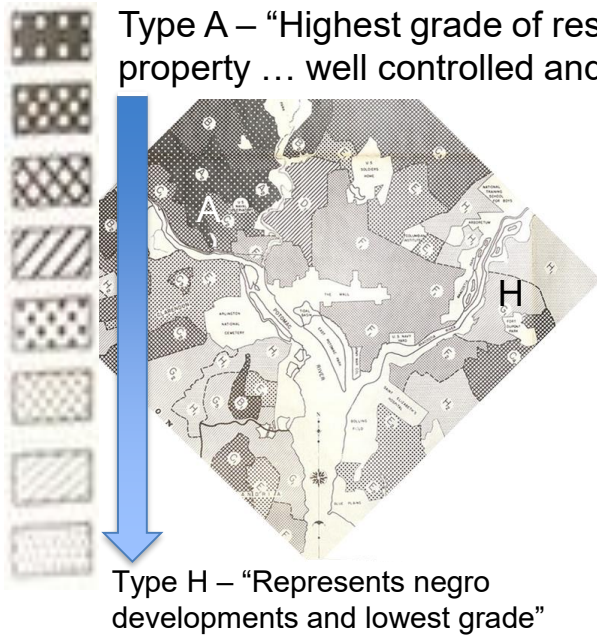National Institute on Minority Health and Health Disparities

# Racism as Research Construct

- *Interpersonal*: Most work done, good measures developed, associations established

- *Internalized*: How discrimination effects individuals who are not aware or sublimate; accept cultural or biological inferiority

- *Perceived societal discrimination*: What does an individual perceive happens in society

- *Second-hand effects of racism*: How does a victim of discrimination/racism impact their loved ones or colleagues
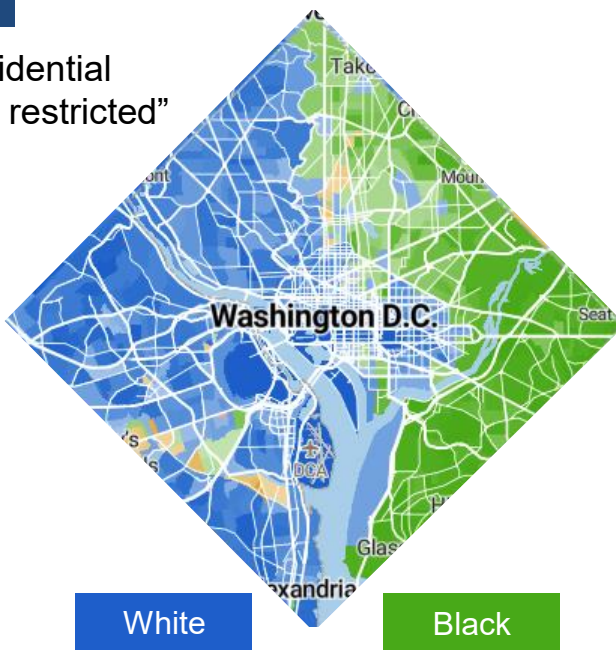
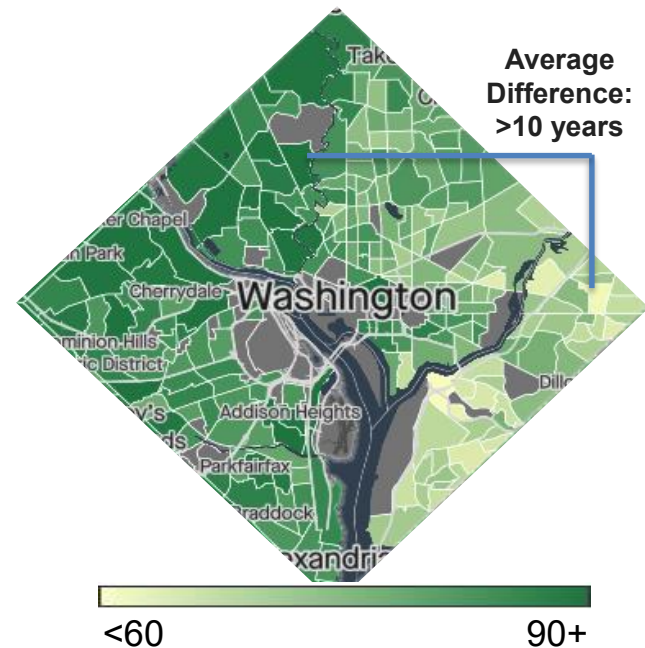# Historical Redlining Policies Influence Social Segregation and Trajectory of Health Outcomes in D.C.



**Federal Housing Administration Residential Market Analysis, 1937**

Type A – "Highest grade of residential property … well controlled and restricted"

Type H – "Represents negro developments and lowest grade"

**Majority Race by Area, 2020**

White — Black

**Average Life Expectancy, 2018**

**Average Difference: >10 years**

<60    90+

8    Source: U.S. National Archives

Bestneighborhood.org
US Census Data

QUARTZ, 2021
CDC Data

Courtesy of Director, National Heart, Lung, and Blood Institute

NIH National Heart, Lung, and Blood Institute

# Community Engaged Research to Reduce Health Disparities: What is Needed?

- **Shift models of care to population health built on strong primary care and community engagement**

- **Recognize the importance of health and not just health care**

- **Engage community resources in promoting health: access to real food and safe places**

- **Recognize and manage structural and interpersonal discrimination at all levels**

# Principles of Community-Engaged Research

- **Full partnership required — level the power relations from the start**

- **Listen, go to the community, participate in activities even if not related to the study**

- **Identify potential research in health issues to address in a collaborative approach**

- **Leverage other resources that can be offered**

- **Move at the Speed of Trust**

- **Report back on results**

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https://public.govdelivery.com/accounts/US-NIHNIMHD/subscriber/new

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