

Overcoming Barriers: Achieving Equity in Cohort Studies

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Objectives

- Current state of diversity within cardiovascular cohort studies
- To improve “who” we study, we must improve:
 - “who” we fund
 - “what” we study
 - “how” we study
- Case Example: Risk Underlying Rural Areas Longitudinal Study (RURAL)

Major Cardiovascular Cohorts



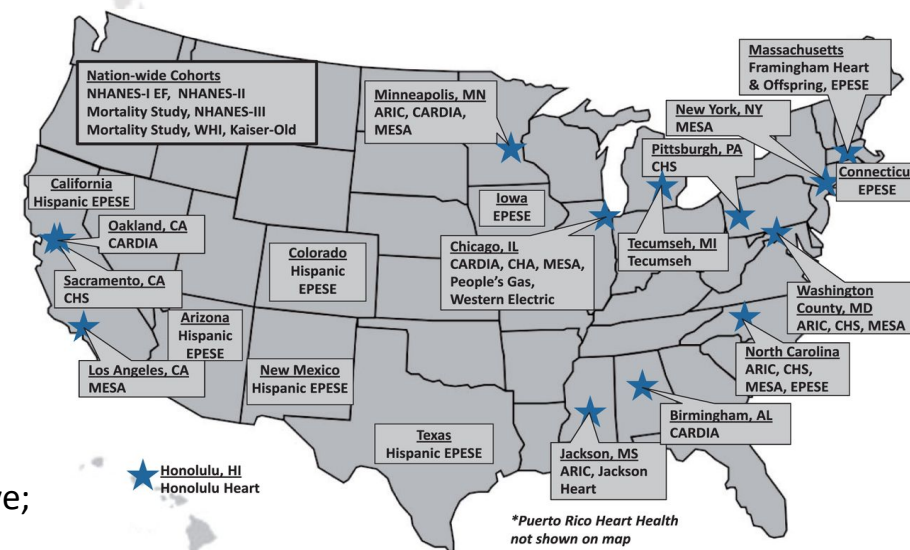
Investigating heart disease
in the South Asian community

	FHS	ARIC	STRONG	CARDIA	MESA	JHS	REGARDS	HCHS/SOL	MASALA
NHW	86	73	0	48.5	38	0	67	0	0
NHB	3	27	0	51.5	28	100	37	0	0
HISP	4	0	0	0	22	0	0	100	0
AA/PI	0	0	0	0	12	0	0	0	100
AI/AN	0	0	100	0	0	0	0	0	0
OTHER	7	0	0	0	0	0	0	0	0

NHW= Non-Hispanic White; **NHB**=Non-Hispanic Black; **Hisp**=Hispanic/Latino;

AA/PI=Asian American, Native Hawaiian, other Pacific Islander; **AI/AN**=Native American, Alaska Native;

Other=groups with small sample sizes; mixed racial, ethnic identity



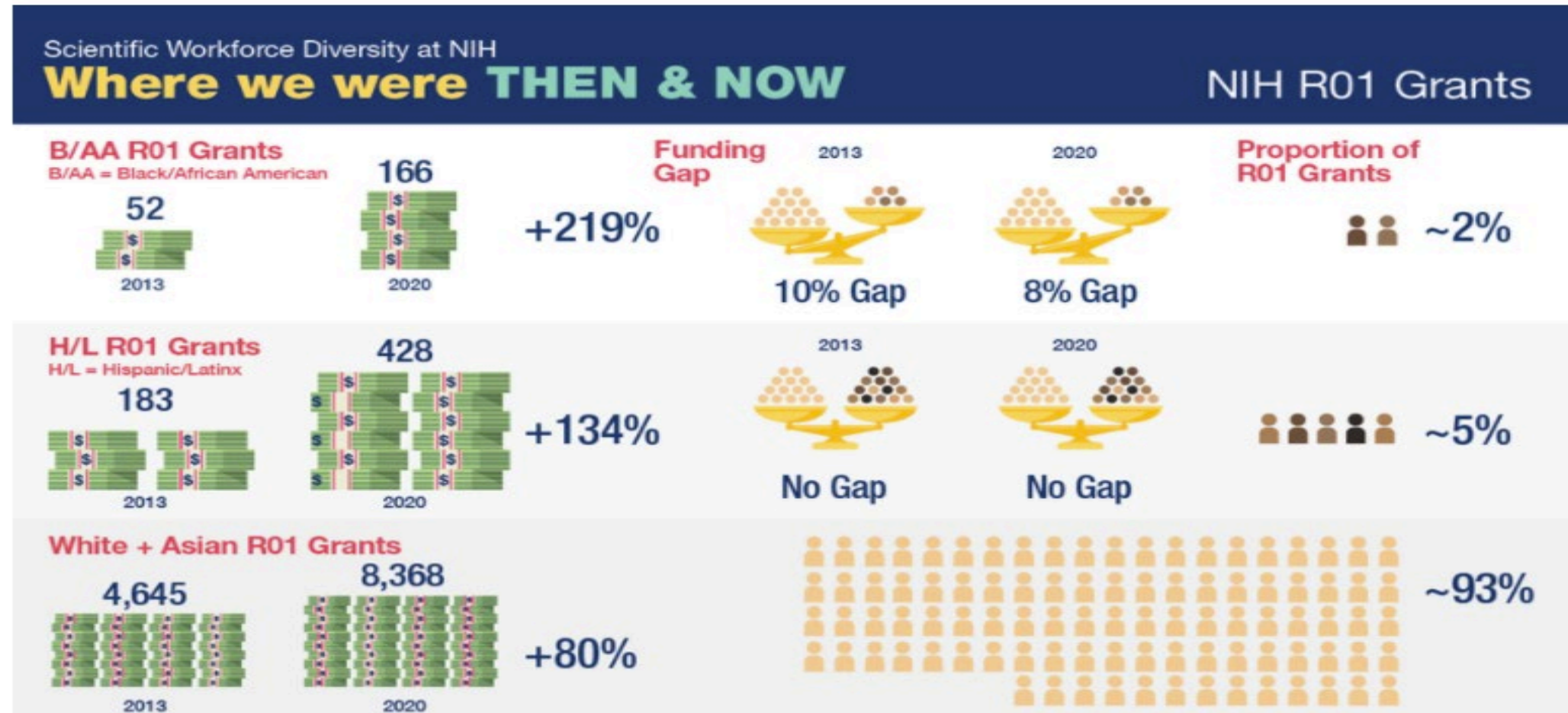
1948

present

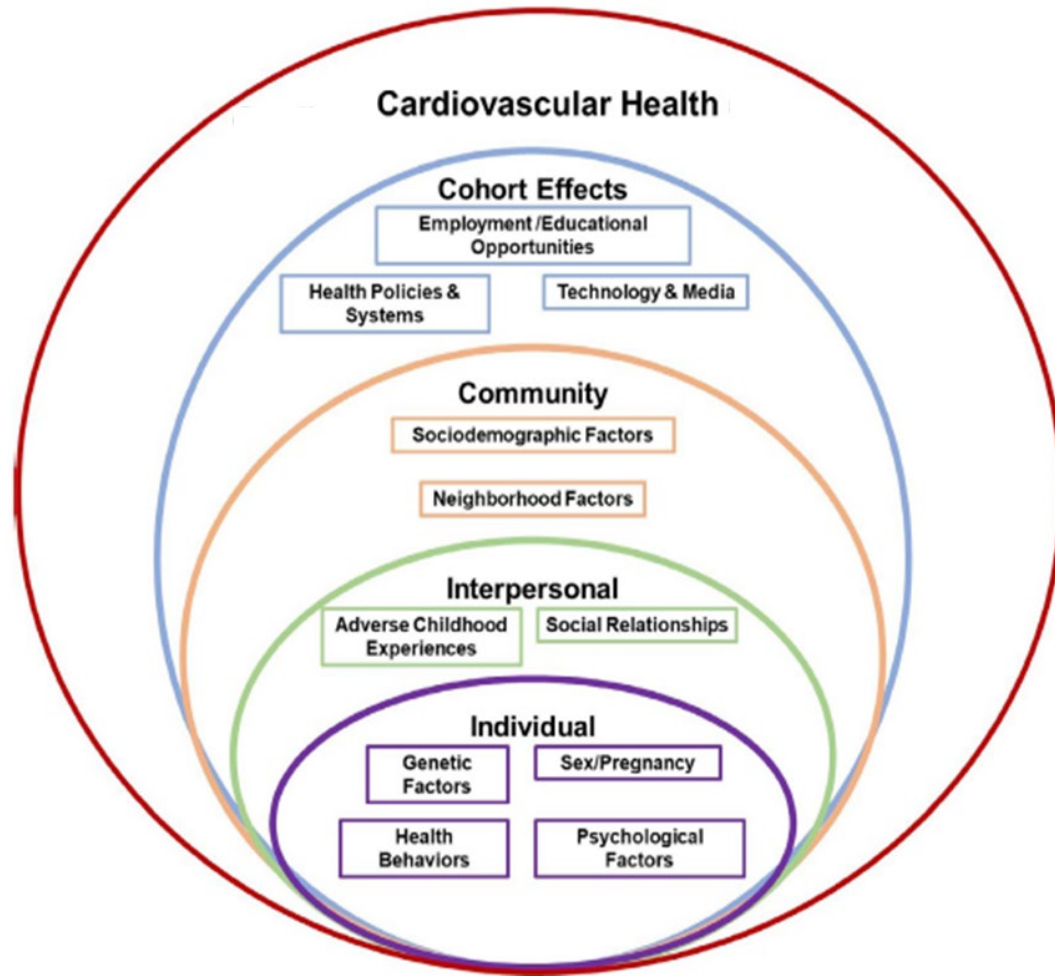
NIH Scientific Workforce Diversity Actions and Progress: Narrowing the Funding Gap

Progress Infographic

“who” we fund



Social Determinants are Key



“what” we study

AHA Scientific Statement

Social Determinants of Risk and Outcomes for Cardiovascular Disease

A Scientific Statement From the American Heart Association

Edward P. Havranek, MD, FAHA, Chair; Mahasin S. Mujahid, PhD, MS, Co-Chair;
Donald A. Barr, MD, PhD; Irene V. Blair, PhD; Meryl S. Cohen, MD, FAHA;
Salvador Cruz-Flores, MD, FAHA;
George Davey-Smith, MA(Oxon), MD, BChir(Cantab), MSc(Lond);
Cheryl R. Dennison-Himmelfarb, RN, PhD, FAHA; Michael S. Lauer, MD, FAHA;
Debra W. Lockwood; Milagros Rosal, PhD; Clyde W. Yancy, MD, FAHA; on behalf
of the American Heart Association Council on Quality of Care and Outcomes Research,
Council on Epidemiology and Prevention, Council on Cardiovascular and Stroke Nursing,

“The most significant opportunities for reducing death and disability from CVD in the United States lie with addressing the social determinants of cardiovascular outcomes”

~American Heart Association Scientific Statement 2015

View Current Funding Opportunities

Understanding and Addressing the Impact of Structural Racism and Discrimination on Minority Health and Health Disparities (R01 Clinical Trial Optional)

This initiative will support (1) observational research to understand the role of structural racism and discrimination (SRD) in causing and sustaining health disparities, and (2) intervention research that addresses SRD in order to improve minority health or reduce health disparities.



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Declarations of Racism as a Public Health Issue

Across the country, local and state leaders are declaring racism a public health emergency. These declarations are an important first step in the movement to a racial equity and justice and must be followed by allocation of resources and strategic action.

Topics & Issues

Health Equity

Racism and Health

Categories: Diversity/Health Equity, Program News | Published: January 25, 2020

More than \$230 million committed to support equitable health for all people

The American Heart Association m...
pledge to aggressively address soci...
working to improve the health of al...
suburban and rural

Historical Trauma and Structural Racism must be Acknowledged

Annals of Internal Medicine®

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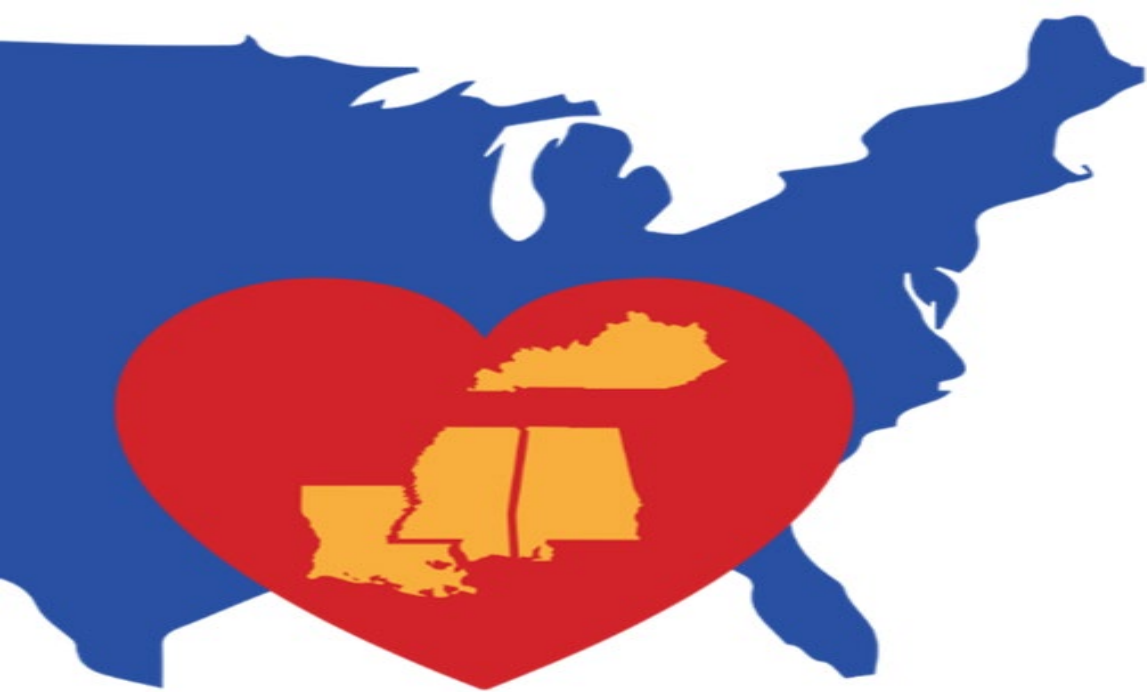
Racism and Health in the United States: A Policy Statement From the American College of Physicians

Josh Serchen, BA, Robert Doherty, BA, Omar Atiq, MD, David Hilden, MD, MPH, ... See More +

Circulation

AHA PRESIDENTIAL ADVISORY

Call to Action: Structural Racism as a Fundamental Driver of Health Disparities
A Presidential Advisory From the American Heart Association



RURAL

Risk Underlying Rural Areas Longitudinal Study

**Supporting healthy hearts
in the rural South**

<https://www.theruralstudy.org/>



Getting Back to the Basics!

“how” we study

- ❑ **Check assumptions** about community members as statistics (individual may fall well above or below the average income or education level for area)
- ❑ Be aware of your **positionality and biases**
 - Be willing to share information about yourself as a person, rather than as a researcher
 - Be open to different viewpoints
- ❑ Exercise ***deep listening*** – don’t be thinking about how their responses fit into your agenda, really quiet your inner voice and listen
 - Be responsive to the feedback you receive
- ❑ **Don’t rush the process**—building relationships take time
 - Rushing creates an climate of distrust and disrespect

What we Learned

- ❑ **Every rural community is distinct**; ask longtime residents about local history and recent changes
 - Unique strategies have to be context specific; there is no one size fits all!
- ❑ **Hire locally** with equitable salaries and benefits and be transparent about financial commitment to local area
- ❑ Use a **mix of recruitment strategies**
 - Face-to-face is ideal
 - Personal phone calls, emails, frequent virtual meetings
 - Dissemination of reader-friendly and relevant materials across different media platforms
- ❑ Engage with **key stakeholders** and tap into established **staples of the community**
 - Local churches and businesses; physicians, barbers/beauticians etc.
- ❑ Understand that the most **effective approach** may not be the most “**efficient**” or “**novel**” approach

Barriers

Time is a social determinant of health



Fairly compensate participants; remove barriers to compensation; slow down; timelines have to be adjusted and responsive to the natural rhythm of the community

Research
hesitance/unfamiliarity



Carefully and humbly explain the research process; Study participants are the experts of their own health; value their lived experience

Medical mistrust, health care
discrimination, and structural
racism



Acknowledge it; measure it; give it equal weight to other aspects of the study





Thank you!

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