

# Community-Engaged Research to Address Cardiometabolic Health Disparities

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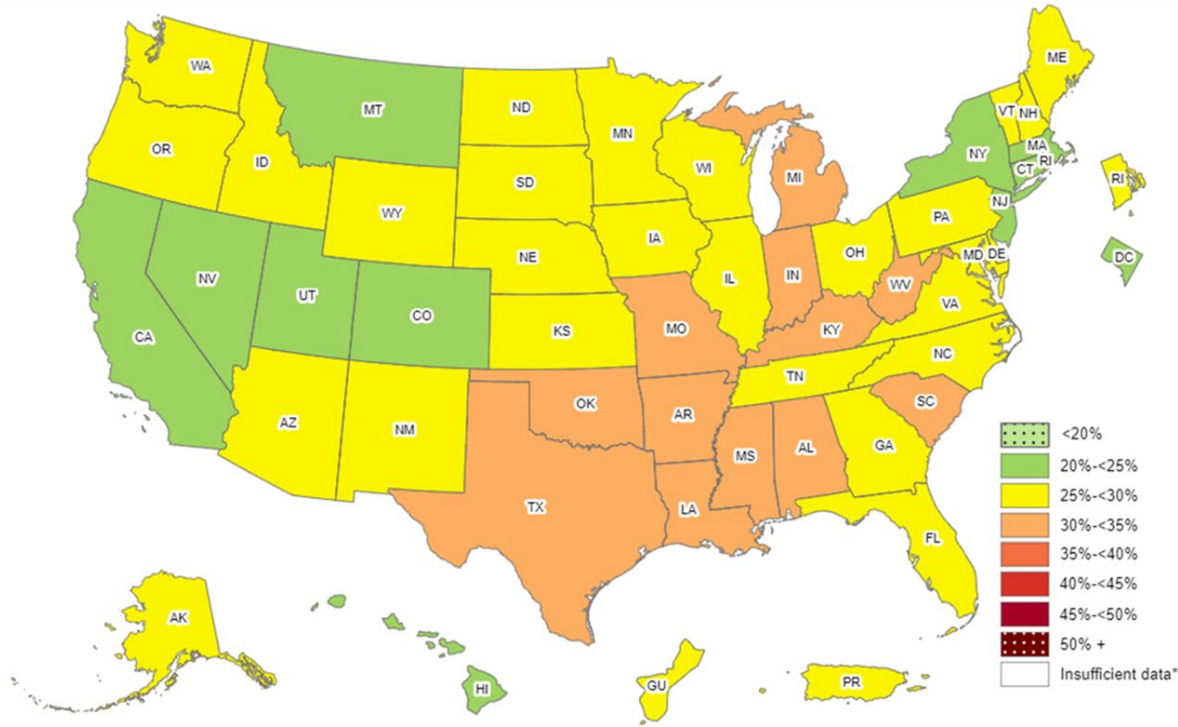
September 12, 2024



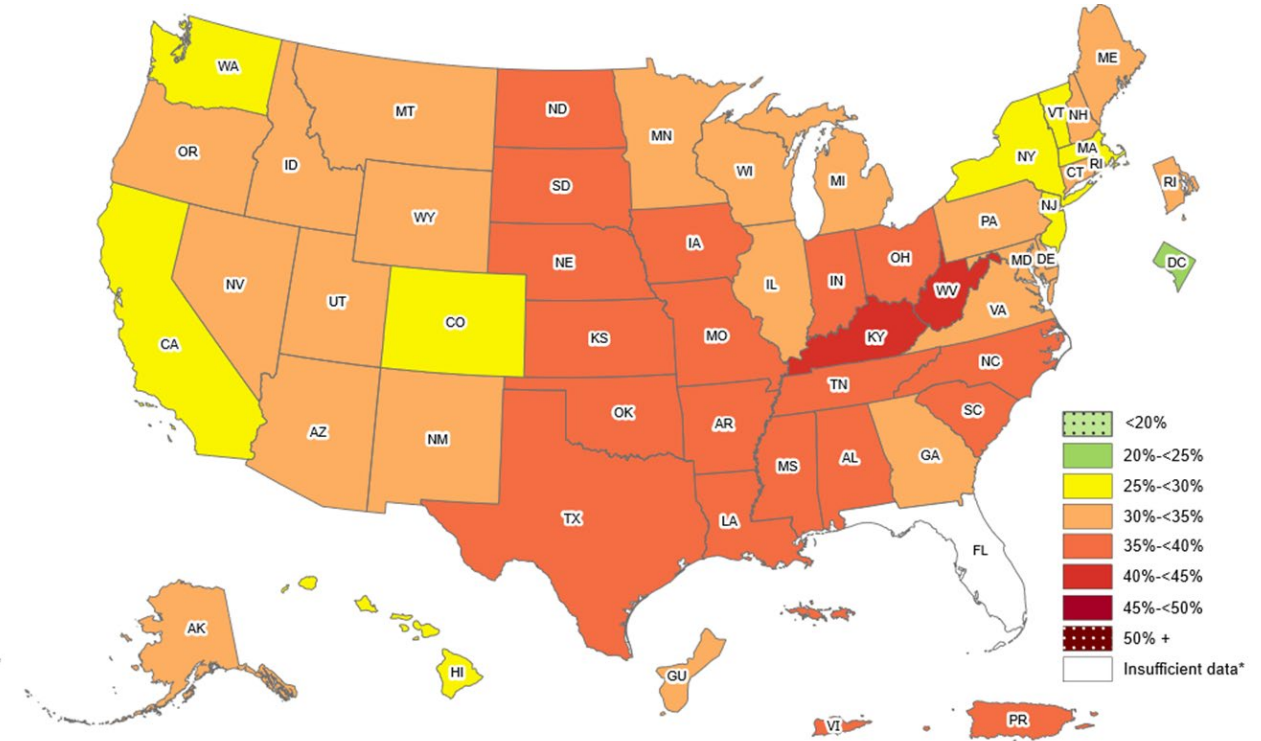
# Learning Objectives

- Define community engagement and community-based participatory research (CBPR)
- Describe the role of community engagement in addressing cardiometabolic disease impacted by social determinants of health
- Illustrate the role of community-engaged research and CBPR in addressing clinical trial diversity

# Obesity Trends are Worsening in the U.S. (2011 to 2021)



2011



2021

Prevalence of Self-Reported Obesity Among U.S. Adults (BRFSS, CDC, 9/2022)

# Obesity, Diabetes, and Social Determinants of Health Impact CVD Premature Mortality in U.S. (Data from 2000-2015)

Research

JAMA Cardiology | **Original Investigation**

## Association of Cardiovascular Disease With Premature Mortality in the United States

Yingxi Chen, MD, PhD; Neal D. Freedman, PhD; Paul S. Albert, PhD; Rachel R. Huxley, PhD; Meredith S. Shiels, PhD; Diana R. Withrow, PhD; Susan Spillane, PhD; Tiffany M. Powell-Wiley, MD, MPH; Amy Berrington de González, DPhil

- Highest CVD mortality rates remain among NH Blacks
- Increasing CVD mortality for Native Americans/Alaska Natives
- Stagnant CVD mortality rates for young NH White women (age 25-49)
- Counties with higher rates of obesity, diabetes and lowest levels of education with highest premature CVD mortality

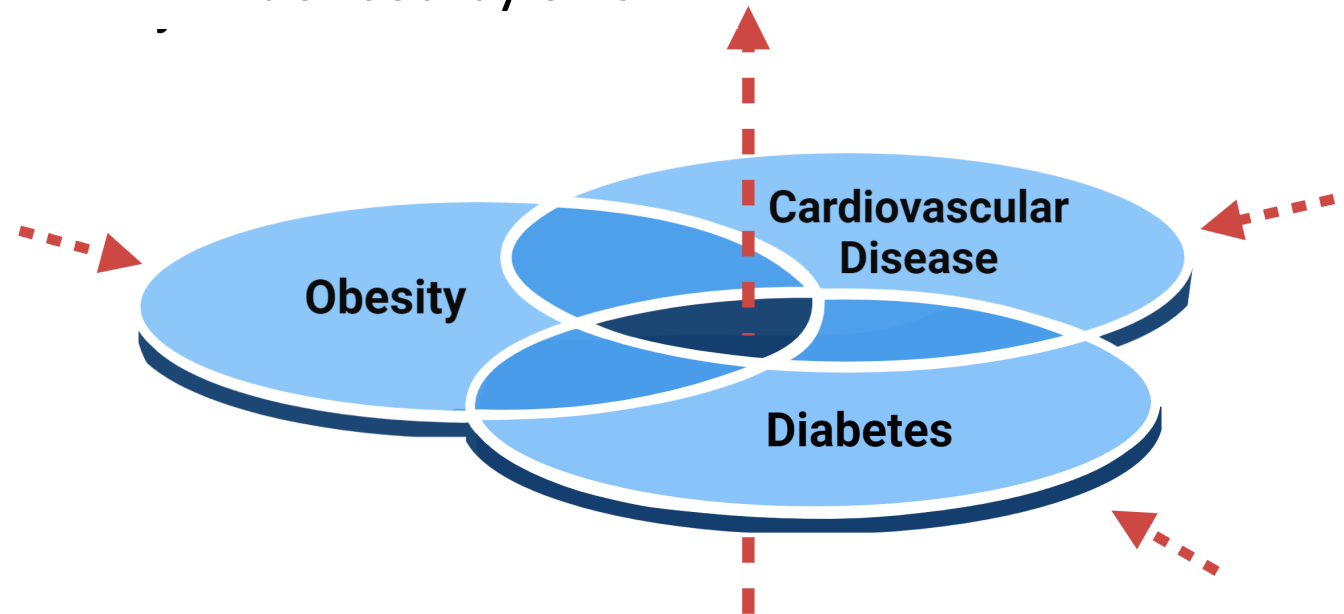
# Syndemic of Obesity, Diabetes, and Cardiovascular Disease

- Several pandemics acting synergistically
- Influenced by social determinants of health (SDoH) and structural inequalities
- Biologic pathways connecting social factors to diseases
- Need for cross-cutting solutions to promote health equity

## Adverse Social Determinants of Health

Diseases are:

- Intersectional
- All influenced by SDoH



Rizzo M. Curr Med Chem 2024

Al Mahmeed W et al. Frontiers CV Med 2021

Mendenhall E et al. Curr Opin HIV AIDS 2020

Figure courtesy of: Mario Pita

# Obesity as a Complex, Multi-factorial Disease

## Circulation

### **AHA SCIENTIFIC STATEMENT**

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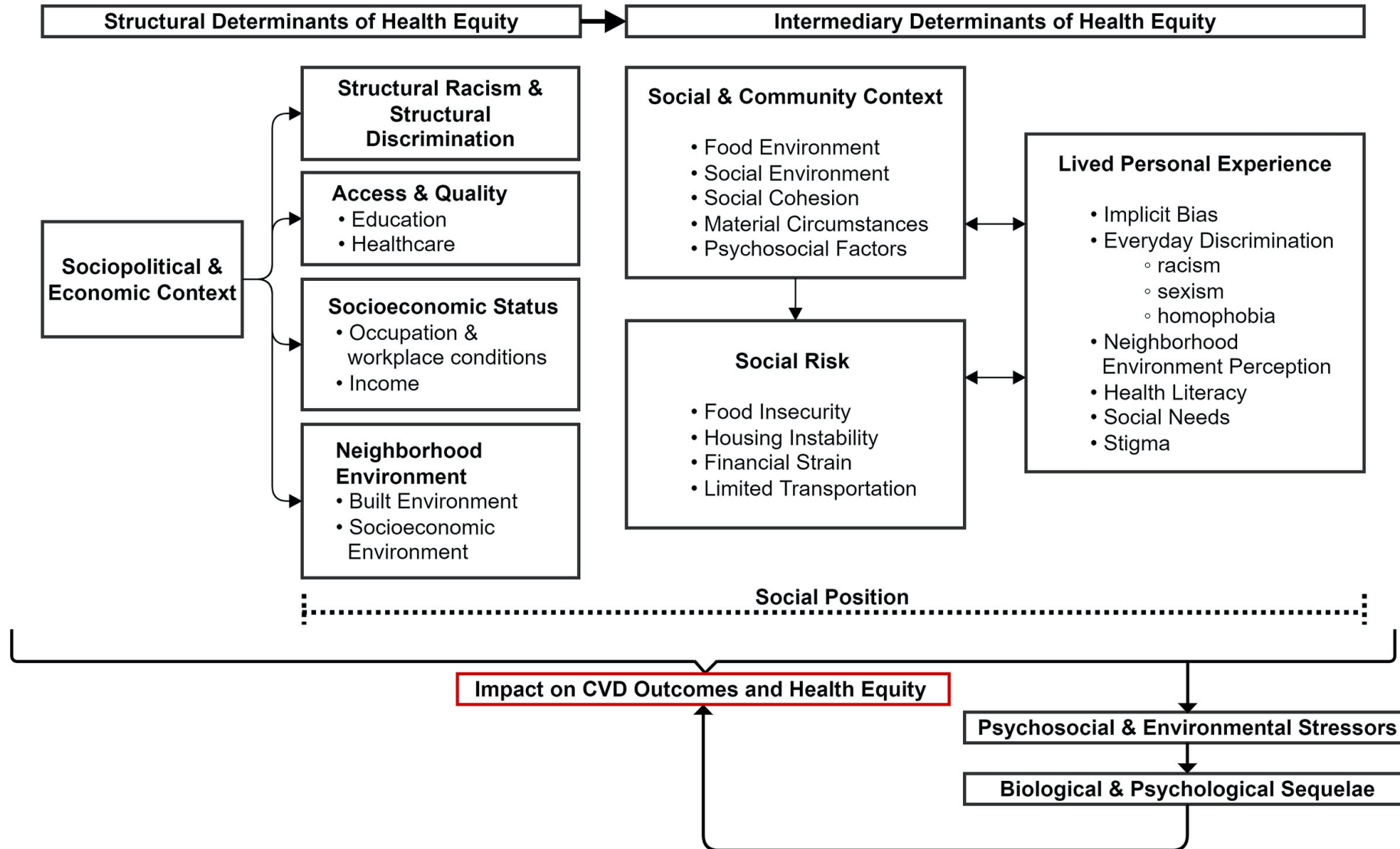
## **Obesity and Cardiovascular Disease**

### **A Scientific Statement From the American Heart Association**

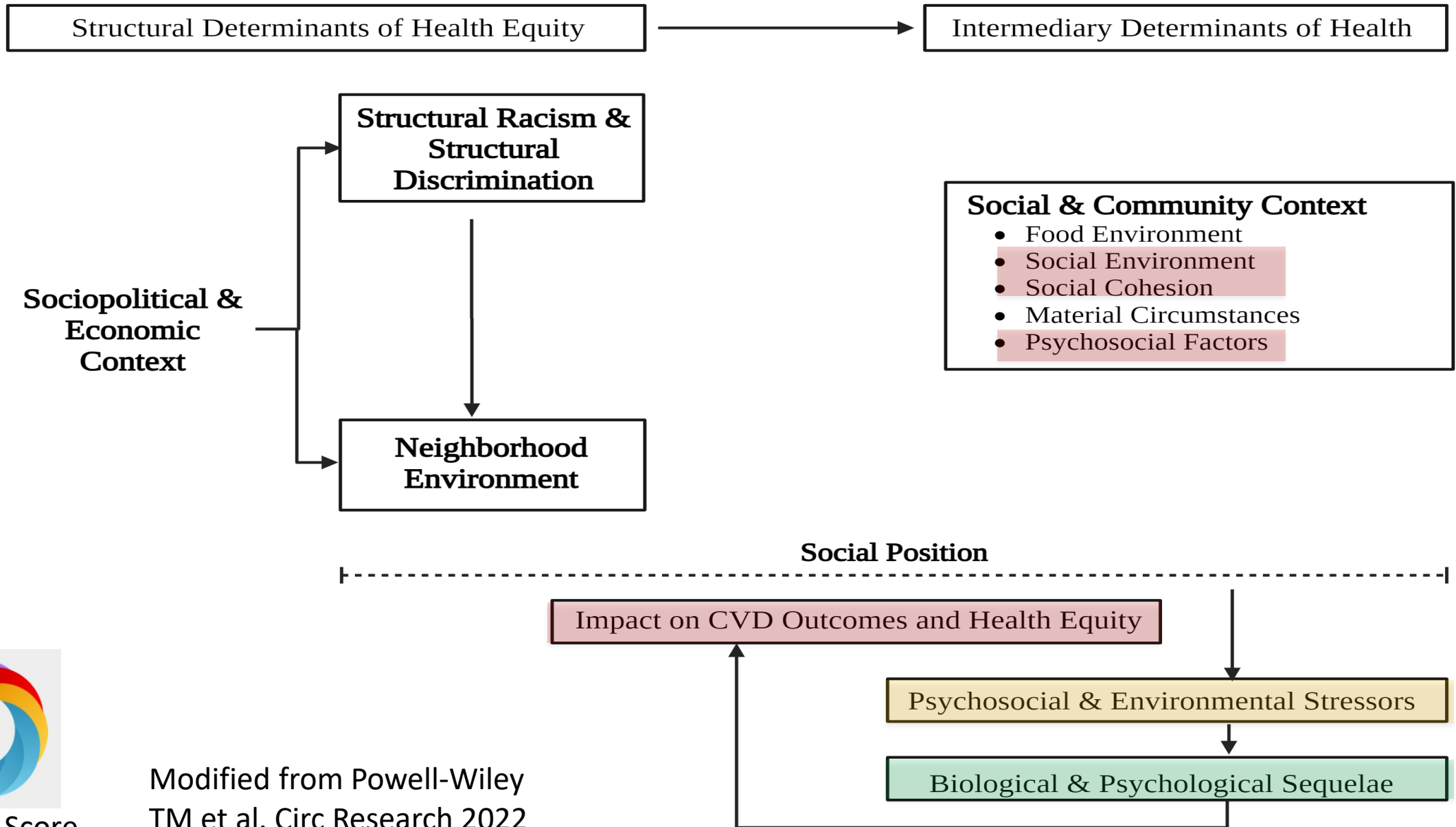
“Obesity is a multifactorial disease with a complex pathogenesis related to **biological, psychosocial, socioeconomic and environmental** factors and heterogeneity in the pathways and mechanisms by which it leads to adverse health outcomes.”

**Social Determinants of Health**

# Equity-Focused Framework for Social Determinants of Health



# Equity-Focused Framework for Social Determinants of Health



Altimetric Score

Modified from Powell-Wiley  
TM et al. Circ Research 2022

# **Community-Engaged Research as a Syndemic Approach**

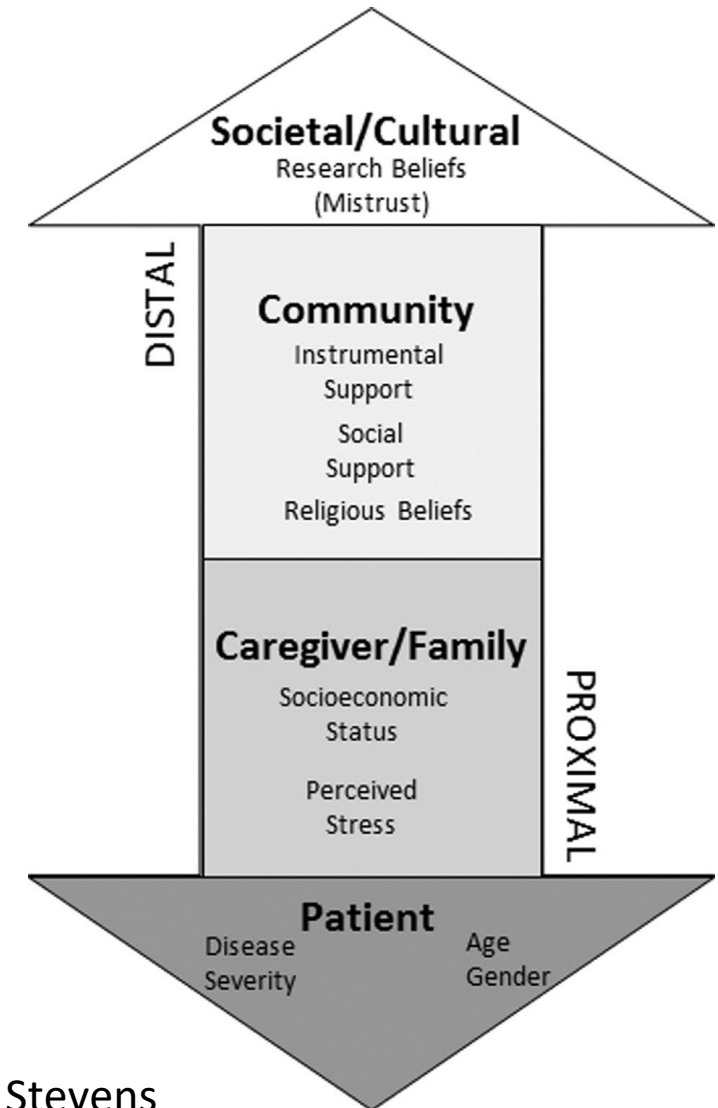
# Definitions of Community

- Populations defined by geography, race/ethnicity, gender, sexual orientation, disability, or health condition
- Groups with common interest or cause
  - Healthcare or service agencies/organizations
  - Healthcare or public health providers
  - Community-based groups with public health concerns
- State, local, and tribal leaders and policy-makers

*Wallerstein, N., Duran, B., Oetzel, J., & Minkler, M. (Eds.). (2018). Community-based participatory research for health: Advancing social and health equity (3rd ed.). Jossey-Bass.*

# Community Engagement can Overcome Mistrust of the Healthcare System and Research

- Historical events contribute to mistrust
- Bias and mistreatment in healthcare system also play role
- Mistrust determined by factors at patient, family, community, and societal levels
- Community engagement for input from those most impacted by health disparities



# Continuum of Community-Engaged Research

Less Community Engagement

Complete Community Engagement



**Researchers** design study and questions

**Community** answers questions

**Community** helps identify issues and research questions and provides some responses

**Researchers** conduct research, analysis, dissemination, design, intervention

**Community** helps identify research question, provides responses, helps generate solutions based on findings

**Researchers** collect and analyze data, disseminate findings, develop interventions based on suggestions

**Community** defines the issues and research questions, creates data collection tools, recruits participants and collects data, analyzes data, disseminates findings and carries out action plan. Full collaborator at all stages.

**Researchers** are collaborators.

# Community Engagement vs. Patient Engagement

	<b>Community Engagement</b>	<b>Patient Engagement</b>
Trust	Built on relationship with academic researcher, academic team, or clinician whose work impacts community	Built on mutual respect and relationship with a clinician or care setting
Source of Common Interest	Interest based on health issue experienced by community	Interest based on personal or family health issue
Perspective or Point of View	Commitment based on public health concerns	Commitment based on experience of medical care
Research Team Stakeholders	Diverse group of community leaders (faith-based organizations, schools, local government)	Primarily clinicians

# Community Engagement Can Increase Representation of Underrepresented Populations in Biomedical Research

- Investigators searched ClinicalTrials.gov for NIH-sponsored cardiovascular disease intervention trials completed between January 1, 2000 and Dec 31, 2019 with  $\geq 1$  clinical site in US

*JAMA* SPOTLIGHT ON RACIAL AND ETHNIC DISPARITIES IN  
CARDIOVASCULAR MEDICINE



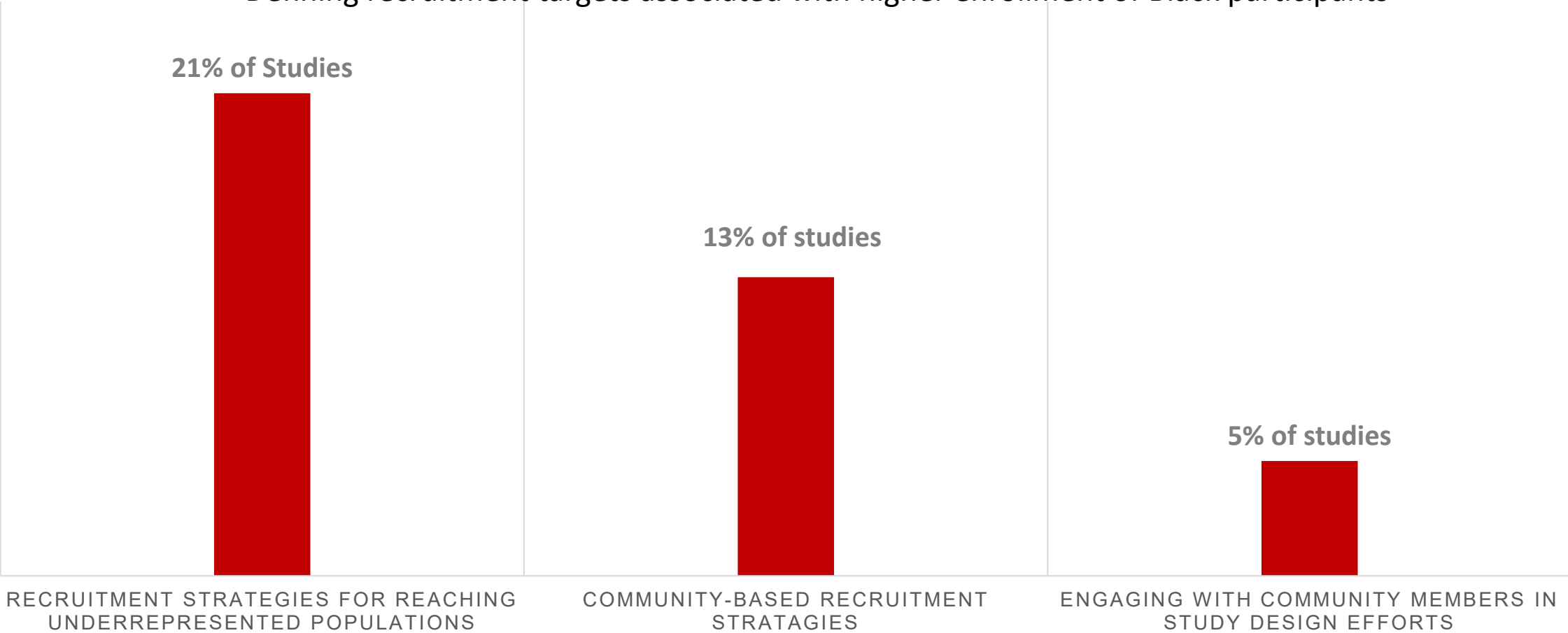
## Recruitment of Black Adults into Cardiovascular Disease Trials

Anagha Prasanna, AB; Hailey N. Miller, PhD; Yingfei Wu, MD, MPH; Anna Peeler, BSN  ;  
Oluwabunmi Ogungbe, MPH  ; Timothy B. Plante, MD, MHS  ; Stephen P. Juraschek, MD, PhD  


*Prasanna A et al. JAMA 2021*

# Community Engagement Can Increase Representation of Underrepresented Populations in Biomedical Research

Defining recruitment targets associated with higher enrollment of Black participants



*Prasanna A et al. JAMA 2021*

# Definition of Community-Based Participatory Research

- A partnership approach to research
- Equitably involves community members, organizations, and academic researchers in all aspects of the research process
- Enables all partners to contribute
- Enhances a common understanding
- Integrates knowledge gained with interventions and policy change

*Wallerstein, N., Duran, B., Oetzel, J., & Minkler, M. (Eds.). (2018). Community-based participatory research for health: Advancing social and health equity (3rd ed.). Jossey-Bass.*

# CBPR Role in Promoting Health Equity

- Communities most affected by health disparities
- Tailor outcomes to specific community needs
- Develop partnerships with trusted community members
- Identify assets of community to improve health outcomes, reduce disparities, and promote equity
- Mobilize community resources towards targeting health disparities

# Key Principles of Community Engagement in CBPR

- Be clear about purposes/goals of effort
- Become knowledgeable about community
- Go into community and build trust/seek commitment among formal and informal leadership



*Wallerstein, N., Duran, B., Oetzel, J., & Minkler, M. (Eds.). (2018). Community-based participatory research for health: Advancing social and health equity (3rd ed.). Jossey-Bass.*

# Key Principles of Community Engagement in CBPR

- Accept that self-determination is right and responsibility of all people who constitute community
- Partner to create change and improve health
- Recognize and respect community diversity



*Wallerstein, N., Duran, B., Oetzel, J., & Minkler, M. (Eds.). (2018). Community-based participatory research for health: Advancing social and health equity (3rd ed.). Jossey-Bass.*

# Key Principles of Community Engagement in CBPR

- Identify and mobilize community assets
- Release control of actions/interventions to community; be flexible to meet changing community needs
- Requires long-term process and commitment



*Wallerstein, N., Duran, B., Oetzel, J., & Minkler, M. (Eds.). (2018). Community-based participatory research for health: Advancing social and health equity (3rd ed.). Jossey-Bass.*

# Core Values of Community Based Participatory Research

- Trust
- Respect
- Self-determination
- Mutuality of interests
- Perspective taking
- Full participation
- Reciprocity
- Collective benefit
- Long-term commitment

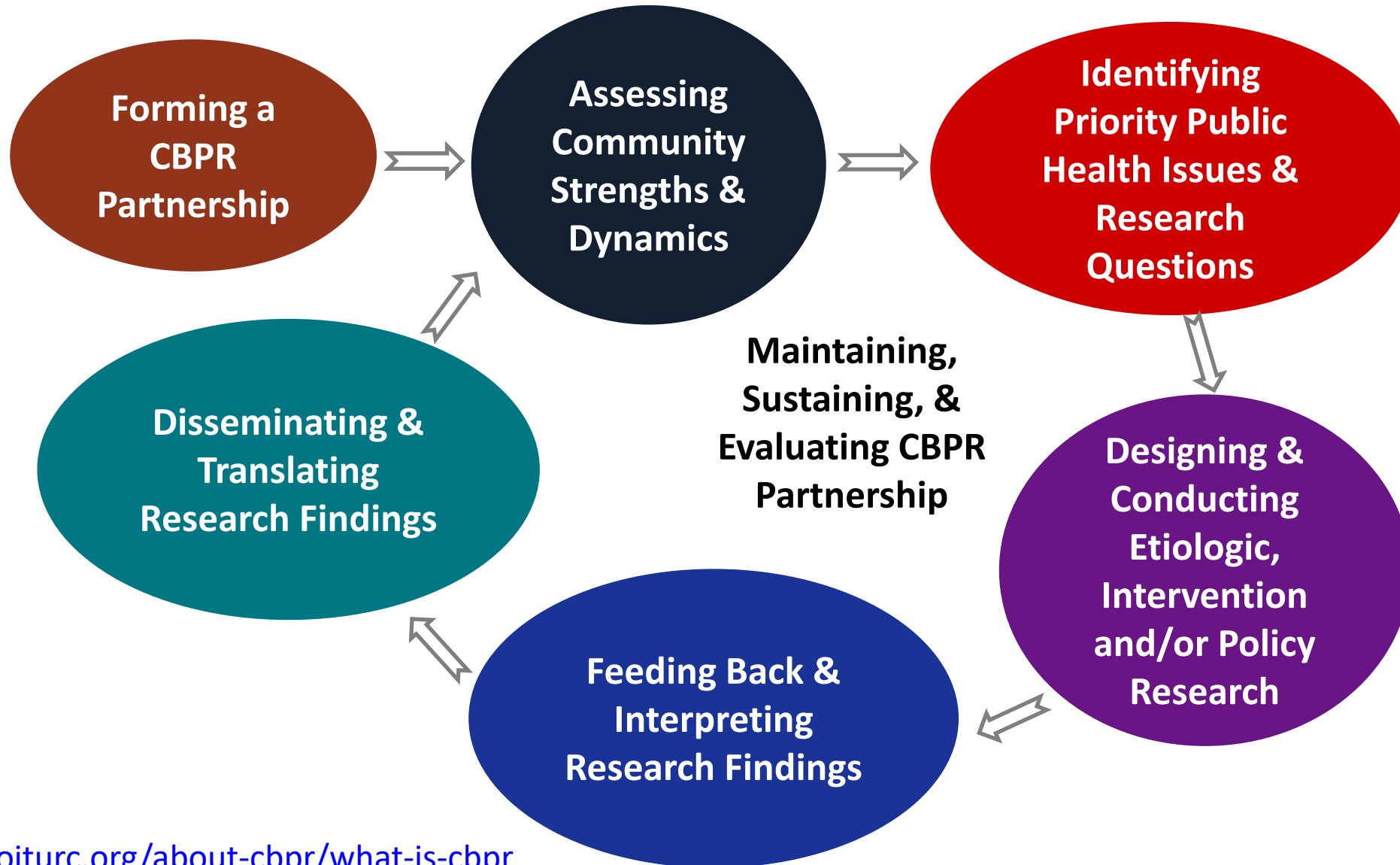
*Wallerstein, N., Duran, B., Oetzel, J., & Minkler, M. (Eds.). (2018). Community-based participatory research for health: Advancing social and health equity (3rd ed.). Jossey-Bass.*

## CBPR: What it is and isn't

- **CBPR is an approach** to research
  - Changes the role of researcher/agency and researched
- CBPR is **not** a specific method or set of methods
  - Can involve qualitative and quantitative methods
  - Can involve multiple research designs (observational studies and/or randomized trials)
- CBPR goal is to influence change in community health, norms, systems, programs/policies

*Wallerstein, N., Duran, B., Oetzel, J., & Minkler, M. (Eds.). (2018). Community-based participatory research for health: Advancing social and health equity (3rd ed.). Jossey-Bass.*

# Core Components and Phases in Conducting CBPR



# Challenges in Academia-Community Relationships

- Nuances of participation and community consent (who is participating/who is not)
- Power and privilege: Who sets the research question? Who has power of knowledge?
- Historical research abuse/stereotyping/racism
- Be willing to face the reality of negative history

*Wallerstein, N., Duran, B., Oetzel, J., & Minkler, M. (Eds.). (2018). Community-based participatory research for health: Advancing social and health equity (3rd ed.). Jossey-Bass.*

# Challenges in Researcher-Community Relationships

- Academic vs. community time: publishing versus taking action
- CBPR cyclical and iterative process: research goals are not always known at the beginning of work
- Research team having necessary skills (cultural humility, listening, sharing decision-making)

*Wallerstein, N., Duran, B., Oetzel, J., & Minkler, M. (Eds.). (2018). Community-based participatory research for health: Advancing social and health equity (3rd ed.). Jossey-Bass.*

# Benefits of CBPR

- Enhances relevance of research questions to the communities at highest risk
- Enhances reliability and validity of measurement instruments
- Improves response rates
- Enhances recruitment and retention
- Strengthens intervention by incorporating cultural beliefs into scientifically valid approaches

*Wallerstein, N., Duran, B., Oetzel, J., & Minkler, M. (Eds.). (2018). Community-based participatory research for health: Advancing social and health equity (3rd ed.). Jossey-Bass.*

# **A Framework for Community Engagement**





Article

# The Communication, Awareness, Relationships and Empowerment (C.A.R.E.) Model: An Effective Tool for Engaging Urban Communities in Community-Based Participatory Research

Joniqua Ceasar <sup>1</sup>, Marlene H. Peters-Lawrence <sup>2</sup>, Valerie Mitchell <sup>1</sup> and Tiffany M. Powell-Wiley <sup>1,\*</sup>

<sup>1</sup> Cardiovascular Branch, National Heart, Lung and Blood Institute, National Institutes of Health, Bethesda, MD 20892, USA; joniqua.ceasar@nih.gov (J.C.); valerie.mitchell@nih.gov (V.M.)

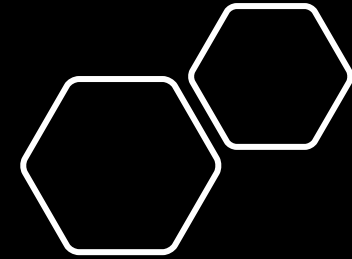
<sup>2</sup> Blood Epidemiology and Clinical Therapeutics Branch, Division of Blood Diseases and Resources, National Heart, Lung and Blood Institute, National Institutes of Health, Bethesda, MD 20892, USA; mpeters@nhlbi.nih.gov

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Received: 6 October 2017; Accepted: 13 November 2017; Published: 21 November 2017

**Abstract:** Little is known about recruitment methods for racial/ethnic minority populations from resource-limited areas for community-based health and needs assessments, particularly assessments that incorporate mobile health (mHealth) technology for characterizing physical activity and dietary intake. We examined whether the Communication, Awareness, Relationships and Empowerment (C.A.R.E.) model could reduce challenges recruiting and retaining participants from faith-based organizations in predominantly African American Washington, D.C. communities for a community-based assessment. Employing C.A.R.E. model elements, our diverse research team developed partnerships with churches, health organizations, academic institutions and governmental agencies. Through these partnerships, we cultivated a visible presence at community events, provided cardiovascular health education and remained accessible throughout the research process. Additionally, these relationships led to the creation of a community advisory board (CAB), which influenced the study's design, implementation, and dissemination. Over thirteen months, 159 individuals were recruited for the study, 99 completed the initial assessment, and 81 used mHealth technology to self-monitor physical activity over 30 days. The culturally and historically sensitive C.A.R.E. model strategically engaged CAB members and study participants. It was essential for success in recruitment and retention of an at-risk, African American population and may be an effective model for researchers hoping to engage racial/ethnic minority populations living in urban communities.

**Keywords:** community-based participatory research; mobile health technology; recruitment; Black/African American; underrepresented populations; health disparities; public health and health promotion

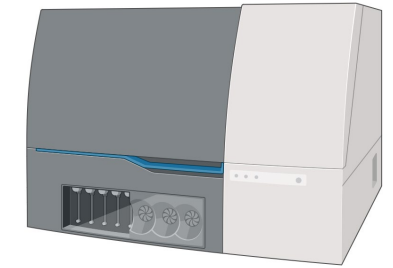
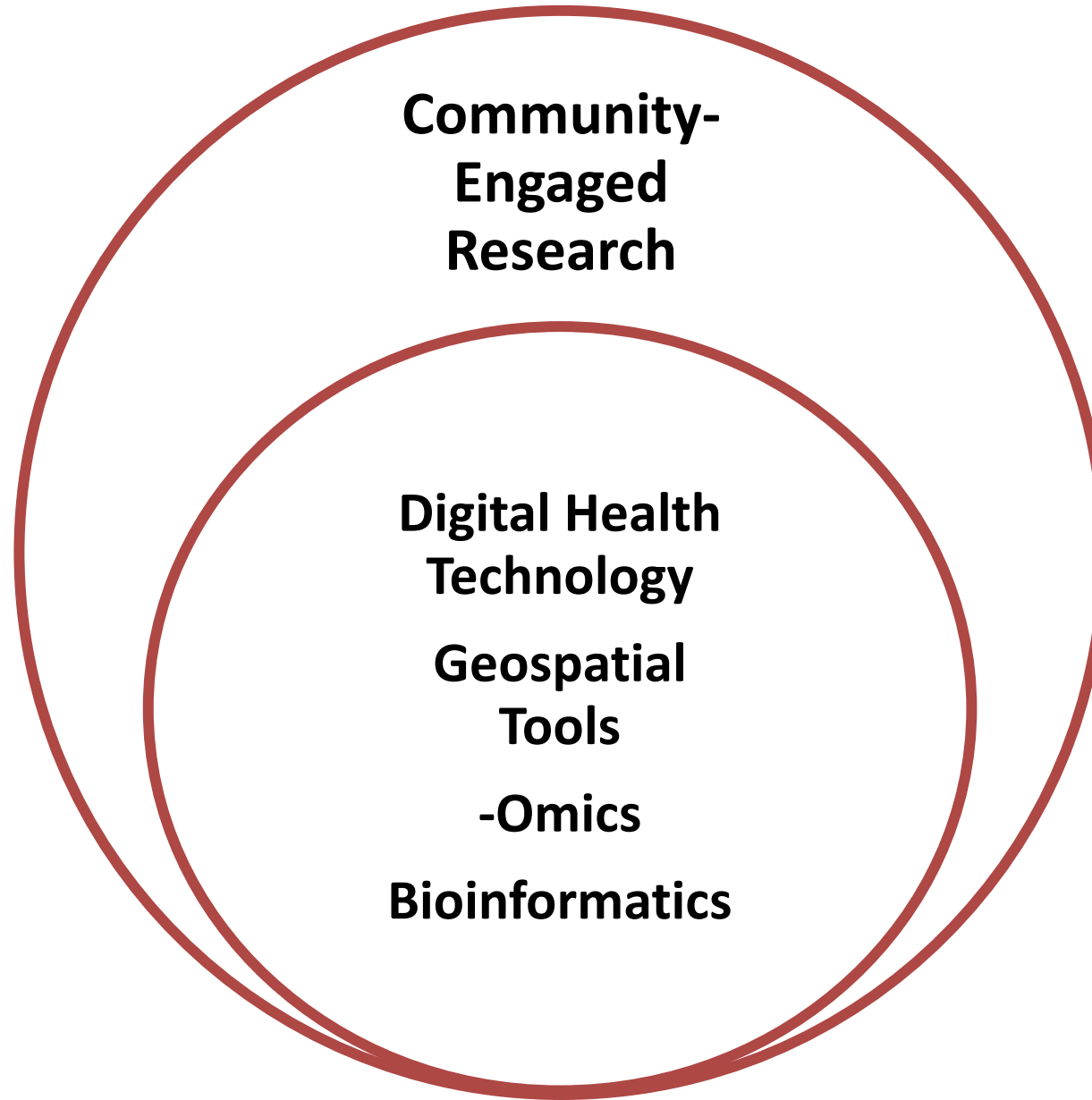


# The C.A.R.E. Model Builds Trust

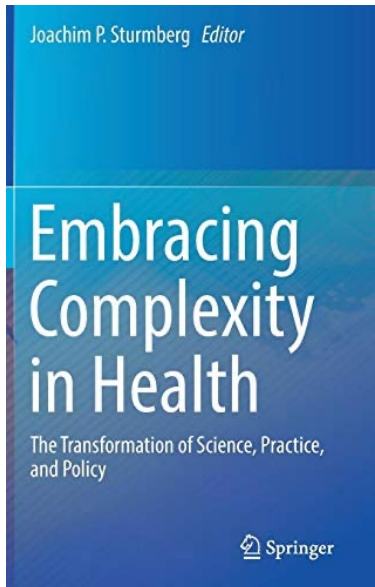


**BUILDS TRUST**

# Novel Integration of Emerging Technology into Community- Engaged Research



Biomarkers as  
Community-Based  
Intervention Targets



DC Metro Area



Urban Cities

# DC Cardiovascular Health and Obesity Collaborative (DC CHOC) Community Advisory Board Evolution of Impact



**DC CHOC Co-Chairs:**  
Rev. Patricia Fears and Mrs. Mary Douglas-Brown

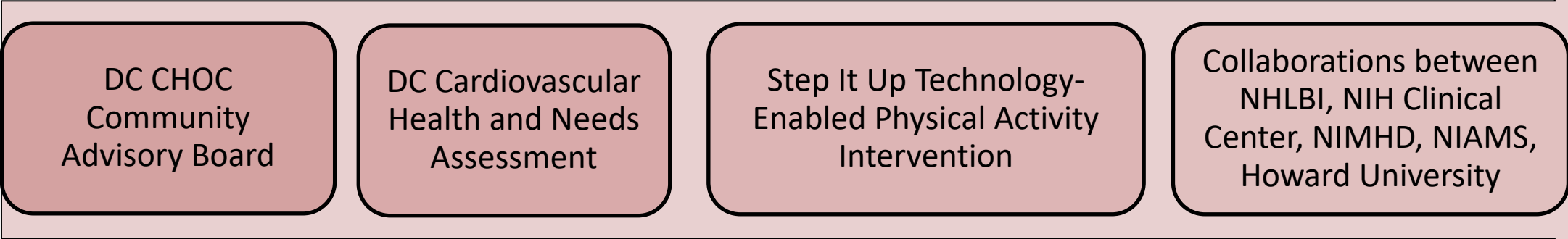


**Powell-Wiley TM et al.**  
Circulation 2023

# DC CHOC Community Advisory Board as First Step in Community-Engaged Research

2012

2020



Ortiz-Whittingham LR et al. Psychoneuroendocrinology 2023\*  
**Powell-Wiley TM** et al. Frontiers CV Med 2021\*  
 Claudel SE et al. J Aging Phys Act 2021\*  
 Claudel SE et al. BMJ Health Care Informatics 2020\*  
 Ceasar J et al. JMIR Formative Research 2019\*

Tamura K, Vijayakumar N et al, BMJ Open 2020 \***Powell-Wiley TM** as senior author

Farmer N et al. Nutrients 2024  
 Farmer N et al. BMJ Health Care Informatics 2022\*  
 Farmer N et al. Frontiers Nutrition 2022

# Step It Up Community-Engaged Physical Activity Intervention



- Adaptive Randomized Trial
- Involves Digital Health Technology (wearables, apps)
- Testing the effects of tailored-to-place messaging about physical activity



## Phases of Intervention Design (Revised ORBIT Model)



Ceasar JN, Claudel S et al. JMIR Formative Research 2019\*; Tamura K, Vijayakumar Net al. BMJ Open 2020\*; Vijayakumar N, Neally S, et al. Circulation CV Quality and Outcomes 2022\*;  
Czajkowski SM et al. Health Psychology 2015 \*Powell-Wiley TM as senior author

BMJ Health &  
Care Informatics

# Use of a community advisory board to build equitable algorithms for participation in clinical trials: a protocol paper for HoPeNET

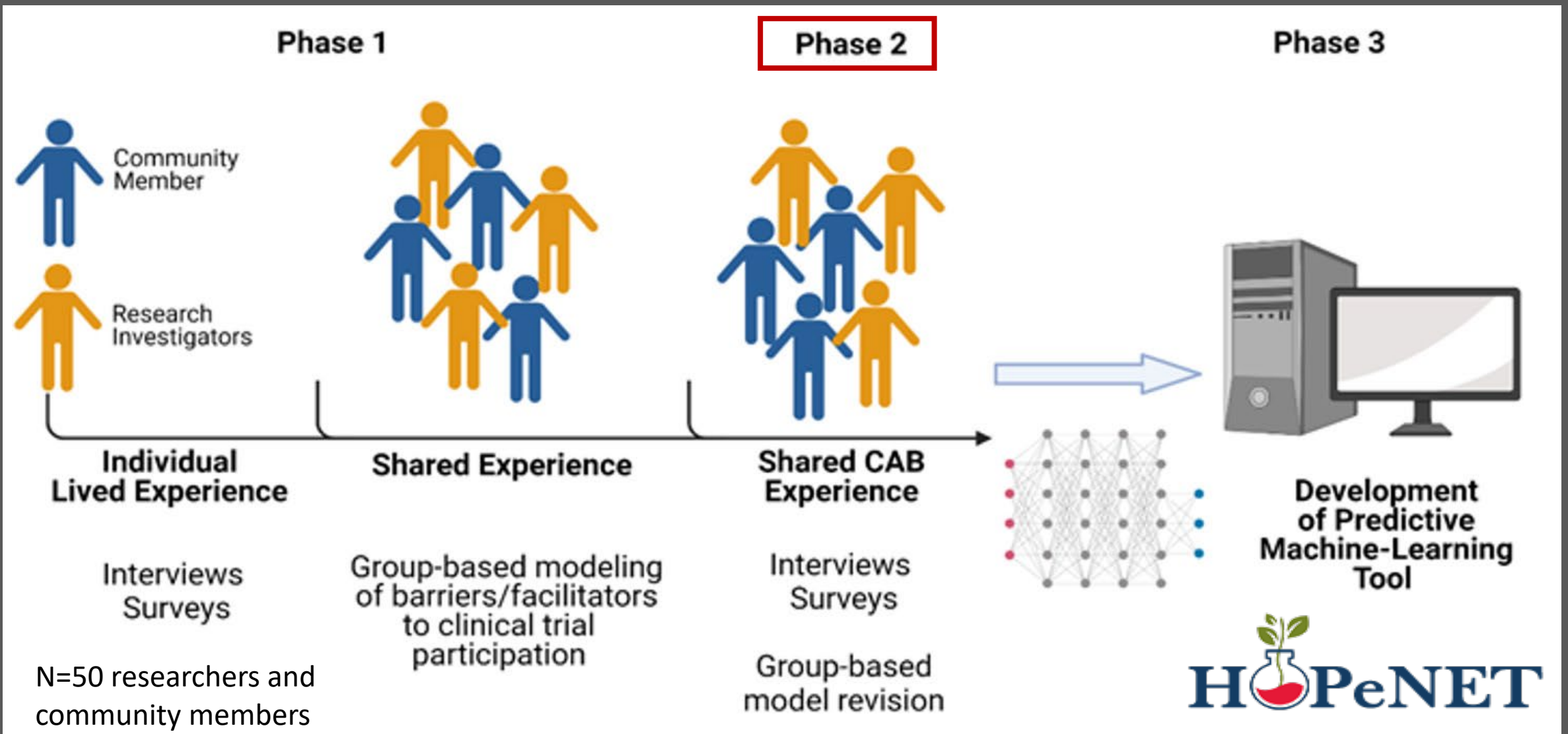
Nicole Farmer,<sup>1</sup> Foster Osei Baah,<sup>2</sup> Faustine Williams,<sup>3</sup> Erika Ortiz-Chapparo,<sup>2</sup> Valerie M Mitchell,<sup>2</sup> Latifa Jackson,<sup>4</sup> Billy Collins,<sup>2</sup> Lennox Graham,<sup>5</sup> Gwenyth R Wallen,<sup>1</sup> Tiffany M Powell-Wiley,<sup>2,3</sup> Allan Johnson<sup>6</sup>

Howard University Partnership with the  
National Institutes of Health for Equitable  
Clinical Trial Participation for Racial/Ethnic  
Communities Under-represented in Research



Genentech

2020 Genentech Health Equity Innovations Fund Award

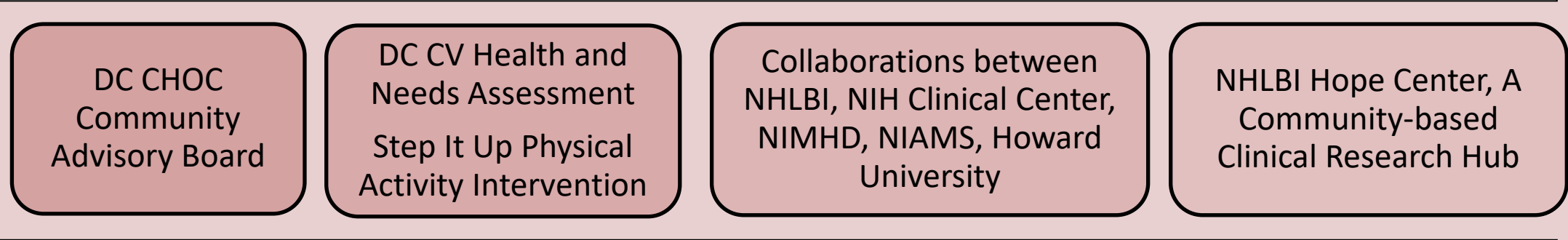


Unstructured and structured data + Qualitative data → Training machine learning tool to model barriers and facilitators to clinical trial participation

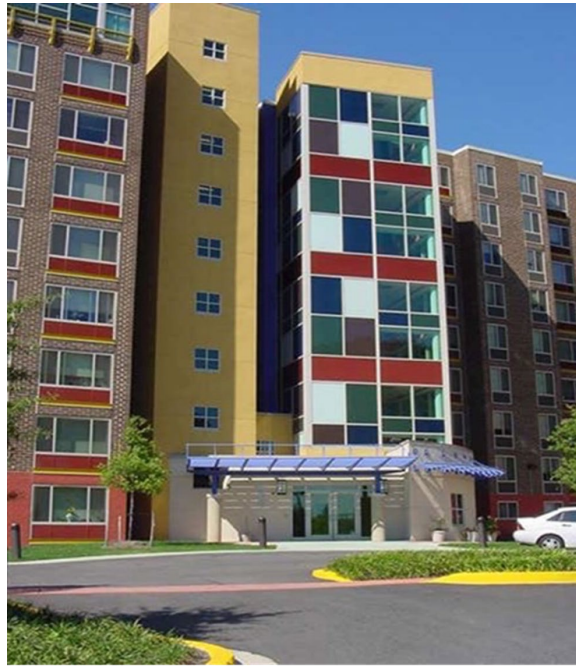
# Development of Community-Engaged Research in NHLBI Division of Intramural Research

2012

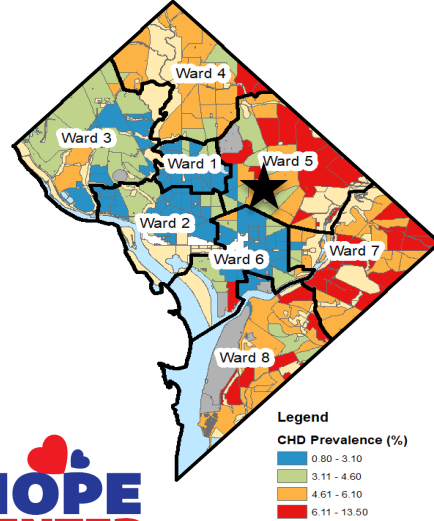
2023



Wells A et al. AJPH 2024 (Accepted)\*  
\*Powell-Wiley TM as senior author



CHD Prevalence



# Community-Engaged Research Hub: NHLBI Hope Center

- Paradigm shift for NIH intramural research enterprise
- Accessible location for clinical research engagement and outreach
- Embedded in an affordable housing development in DC
- Opened in January 2023



# Dissemination of Study Findings Through Community Engagement

- Community Advisory Board meetings
- Community Heartbeats newsletter
- Community events
- Hope Center outreach events
- Website with publications for study participants

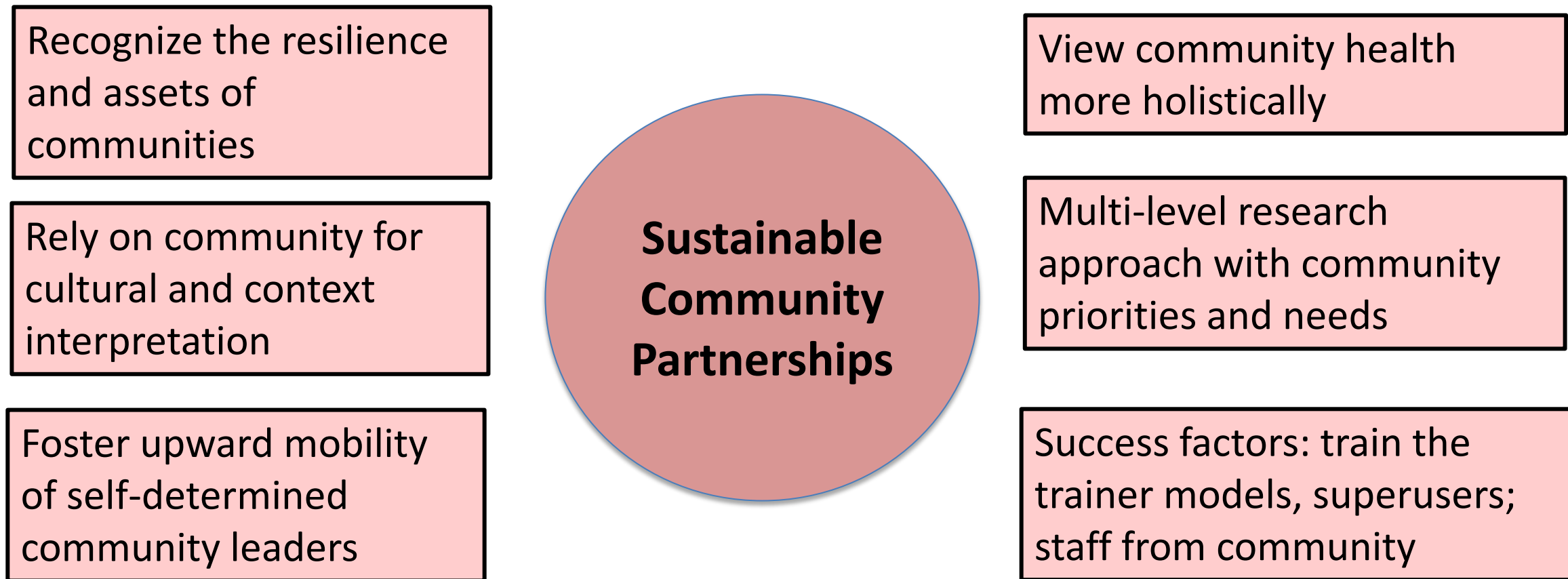


SOCIAL DETERMINANTS OF OBESITY AND CARDIOVASCULAR HEALTH LAB UPDATES  
FALL 2023

## COMMUNITY HEARTBEATS



# Important Strategies in Building Community-Based Partnerships For Reducing Chronic Disease Risk



# Community Engagement to Address the Cardiometabolic Syndemic Through the Healthcare System

## Potential Healthcare System Interventions for Community Engagement

Expand clinical teams with more staff members that address social needs (i.e. social workers, patient navigators, community health workers)

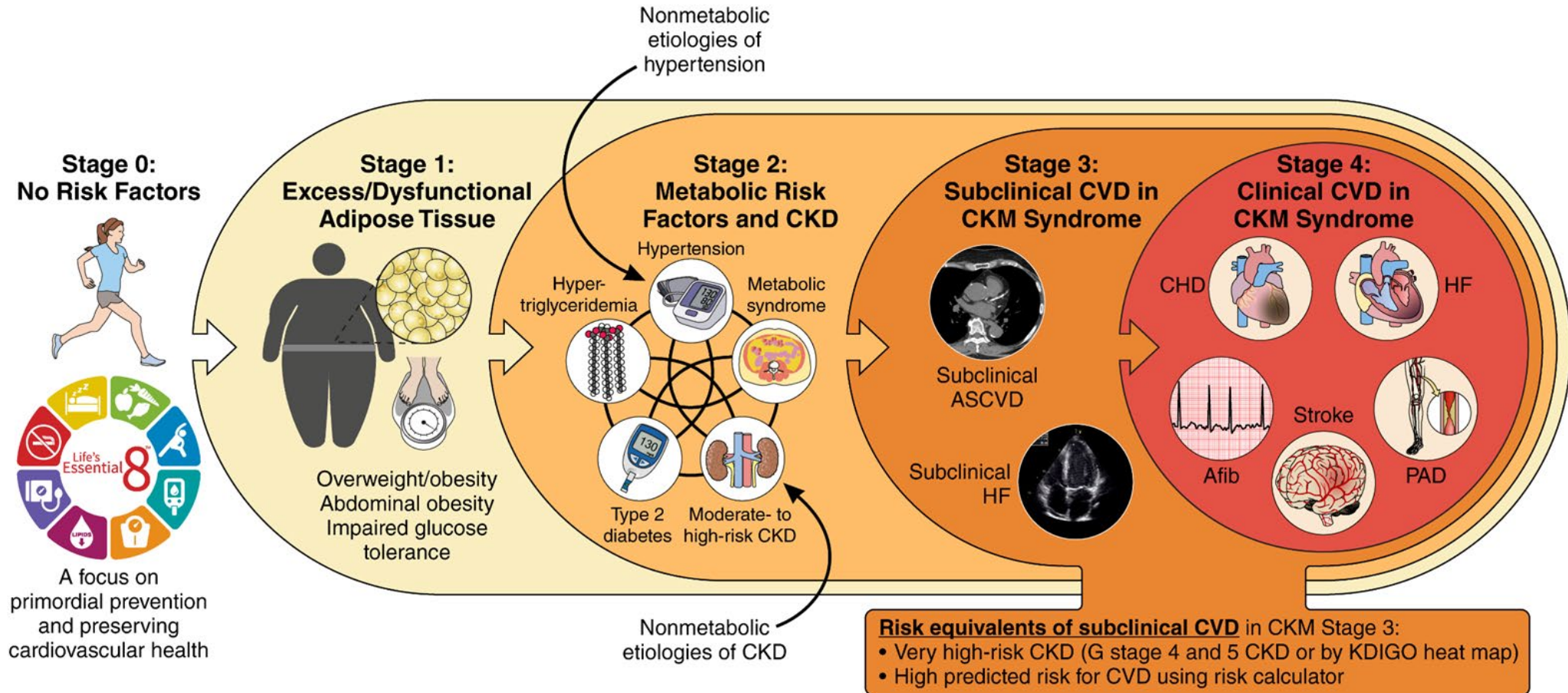
Establish partnerships with community-based organizations to gain community input on new initiatives

Create social needs resource linkage tools for clinician use

Address barriers to coordination between clinical and social services

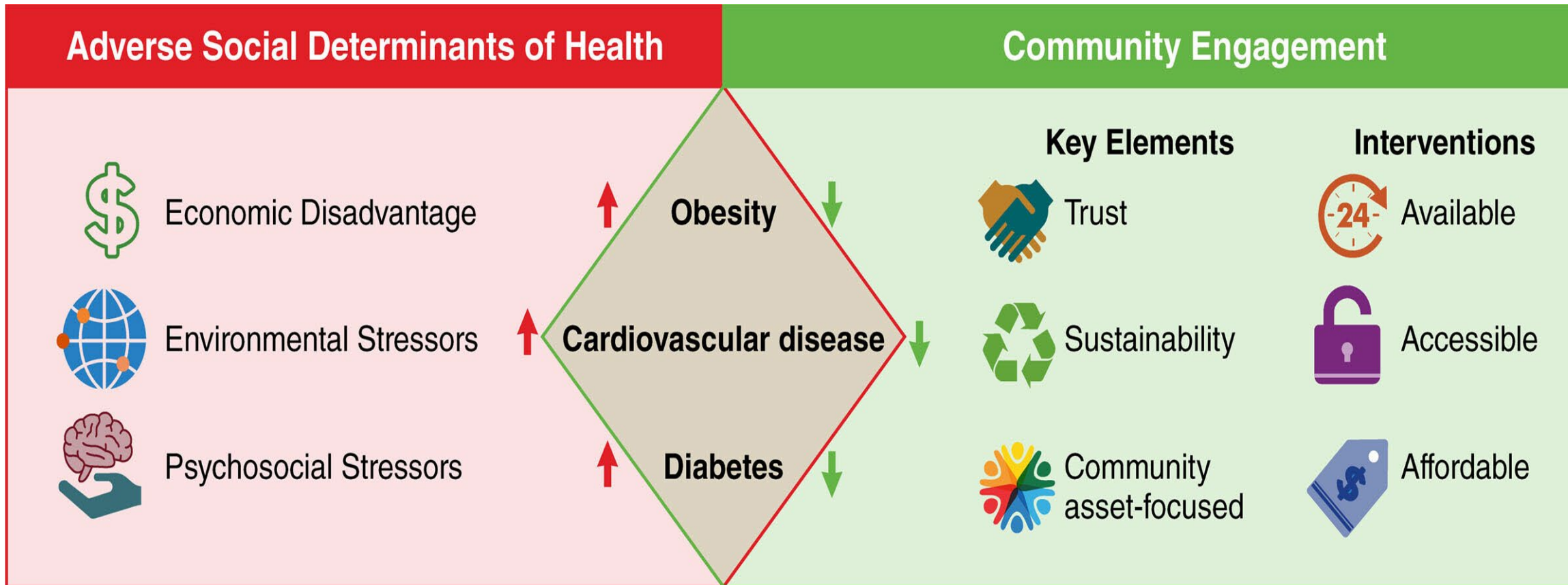
Invest in local social needs resources such as food and housing assistance programs

# Screen for Social Determinants of Health in Care of Cardiovascular-Kidney-Metabolic Syndrome



**Social Determinants of Health Screening**

# Community Engagement To Improve Cardiometabolic Health



Tiffany M. Powell-Wiley. *Circulation*. Centering Patient Voices Through Community Engagement in Cardiovascular Research, Volume: 147, Issue: 2, Pages: 105-107, DOI: (10.1161/CIRCULATIONAHA.122.061112)

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  - Sonal Sharda
  - Joy Tolentino
  - Ayanna Wells
- Dr. James Troendle (Biostatistician)
- Former Lab Members
- Members of DC Cardiovascular Health and Obesity Collaborative
- Collaborators
  - City University of NY
  - Eastern Virginia Medical School\*
  - George Washington University\*
  - Howard University\*
  - Inova
  - NIH
  - Northwestern University
  - UNC Chapel Hill\*
  - UTSW
  - Weill Cornell Medicine\*
  - Washington, DC Faith-based and Civic Organizations

\*Established Materials Transfer Agreement or Reliance Agreement

Figures created with BioRender.com



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