

Social Determinants of Health at the National Institutes of Health

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National Committee on Vital and Health Statistics Hybrid Meeting
Standards for SDOH Data Elements: Successful SDOH Approaches and Challenges
to Promote Health Equity

April 11-12, 2024



National Institute
on Minority Health
and Health Disparities

Outline

- The Ask: Discuss NIH-Funded Research Using SDOH Data
- NIH Investments in SDOH Research
- Research Programs, Projects, Initiatives
- Moving Forward



The National Institutes of Health



Nation's medical research agency

- Federal Government
- Largest source of funding for biomedical research

27 Institutes and Centers

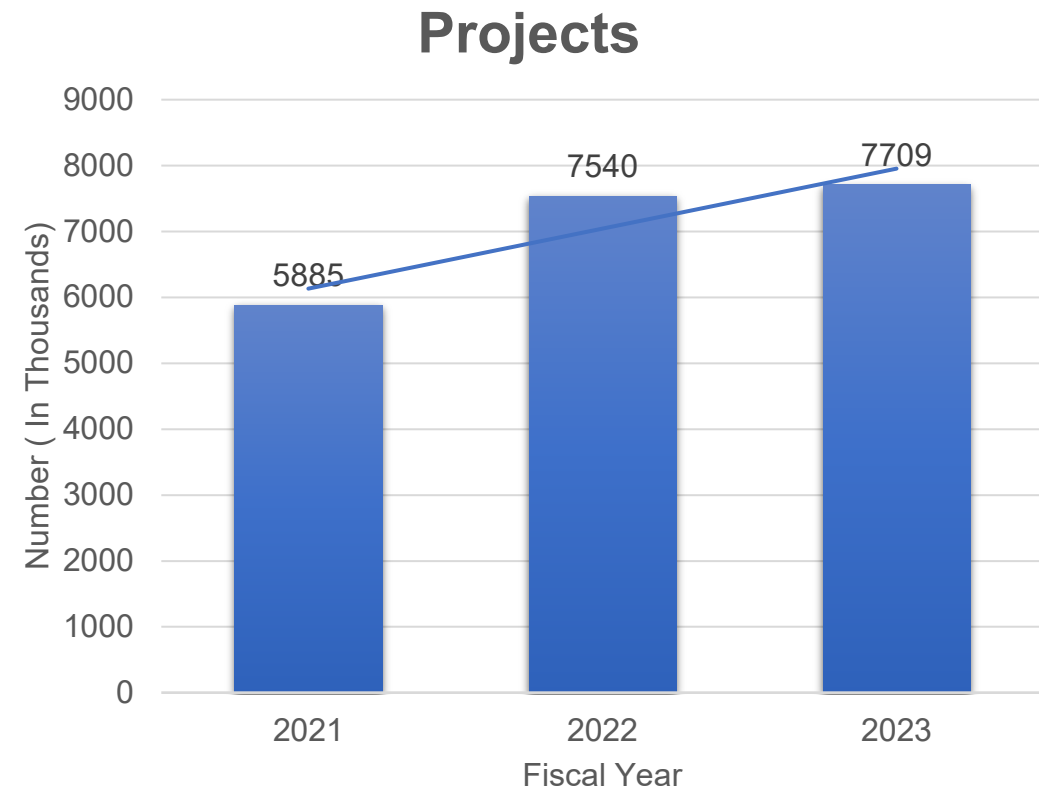
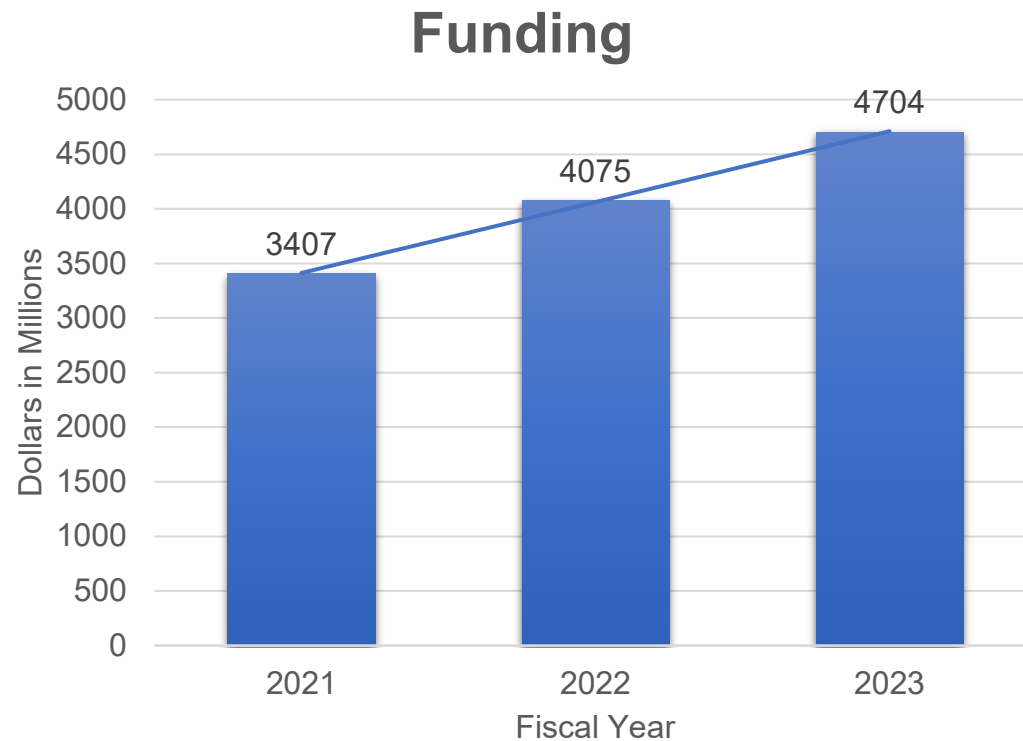
- 75 buildings on 322 acres in Bethesda, Maryland
- Intramural all over the country (NC, MT, AZ, MI, MA)
- Clinical Center (largest hospital dedicated to clinical research in the world)

80% of budget goes to the Extramural community

- Over 2,500 university and research institutions



National Institutes of Health Investment in SDOH Research, FY 2021, 2022 & 2023



■ Funding (Dollars in Millions and Rounded)
— Linear (Funding (Dollars in Millions and Rounded))

■ Projects (Number) — Linear (Projects (Number))



Source: NIH RePORT, Estimates of Funding for Various Research, Condition, and Disease Categories ([RePORT \(nih.gov\)](https://report.nih.gov))



NIH SDOH Related Research Programs, Projects and Initiatives



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The *All of Us* Research Program: An Innovative Research Effort

- **Diversity at the scale of 1 million people or more**
- **Focus on participants as partners**
- **Longitudinal design, ability to recontact**
- **Multiple data types:** EHR, surveys, baseline physical measurements, biospecimens, genomics
- **National, open resource for all:** Broadly accessible to all researchers with open-source software & tools
- **Security and privacy safeguards** for all participant data



The SDOH Survey from *All of Us*

- Launched in November 2021 to collect information about social and environmental factors that influence everyday life
 - Diverse sample; 80% underrepresented in biomedical research
 - Missing Data on certain measures (i.e. race/ethnicity, age, SES)
 - Relaunched the survey with a more targeted and prioritized approach to increase completion rate- later surveys having fewer responses compared to earlier versions

SDoH Survey

Domain	<i>All of Us</i> Measure
Neighborhood Safety	Ross-Mirowsky Perceived Neighborhood Disorder Scale; Social Cohesion Neighborhood Scale (17 items)
Built Environment-Walkability	PANES International prevalence Study (IPS) on Physical Activity (8 items)
Social Support	Rand MOS Social Support Survey Instrument (8 items)
Loneliness	UCLA Loneliness Scale (8 items)
Perceived Discrimination	The Everyday Discrimination Scale (10 items)
Healthcare Discrimination	Discrimination in Medical Settings (adapted from Everyday Discrimination Scale) (7 items)
Food Insecurity	Children's HealthWatch Hunger Vital Sign (2 items)
Housing Insecurity	Health Begins Upstream Risk Screening Tool; Accountable Health Communities (2 items)
Perceived Stress	Cohen's Perceived Stress Scale (10 items)
Daily Spiritual Experiences	Brief Multidimensional Measure of Religiousness/Spirituality: 1999, The NIA/Fetzer Working Group (6 items)
Religious Service Attendance	Nurses Health Study (1 item)

81 questions across 11 subject matter domains;
anticipated time to completion is 10 minutes in English and Spanish



PhenX Toolkit



- Catalog of recommended measurement protocols
- Facilitate cross-study analysis, increasing impact of individual studies; consistent data collection across studies
- Funding: NHGRI.
 - Co-funders: NHLBI, OD, OBSSR, NINDS, NIMHD, NIDA
 - Previous funders



PhenX Toolkit SDOH Core Collection



- SDOH Core Collection Launched in May 2020
 - SDOH Core Collection-16 protocols recommended*
 - Individual SDOH- 23 protocols
 - Structural SDOH- 14 protocols
- Relevant for advancing minority health and health disparities research
- Supports in-depth assessments on SDOH topics
- Low burden protocols; comparable across NIH studies
- CDEs for SDOH Core Collection

SDOH Core Collection	
Access to Health Services	Ethnicity and Race
Annual Family Income	Food Insecurity
Birthplace	Gender Identity
Current Address	Health Insurance Coverage
Current Age	Health Literacy
Current Employment Status	Occupational Prestige
Educational Attainment-Individual	Sex Assigned at Birth
English Proficiency	Sexual Orientation





The National COVID Cohort Collaborative (N3C)

Your Trusted Comprehensive Source for
COVID-19 Patient-Centric Data.

[Get Started](#)[About](#)[Distribution & Demographics](#)

The N3C Data Enclave represents one of the largest secure collections of
harmonized clinical health data in the United States.

-  **Sites:** 83
-  **Persons:** 22.3 million
-  **COVID+ Cases:** 8,754,414
-  **# of Rows:** 32.3 billion
-  **Clinical Observations:** 3.2 billion

-  **Lab Results:** 15.6 billion
-  **Medication Records:** 5.1 billion
-  **Procedures:** 1.2 billion
-  **Visits:** 1.7 billion

Explore Our Dashboards

[Overview](#)[Members](#)[Tracking](#)[Cases](#)[Medications](#)[Diseases & Risk](#)[Factors](#)

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Addressing the Impact of Structural Racism and Discrimination on Minority Health and Health Disparities

- 38 grant awards funded by 14 Institutes and Centers in FY 2022; \$125 Million over 5 years
- The initiative supported: (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.
- Relevant to SDOH by building on institutional racism; neighborhood and community and societal domains that are known to condition additional health risks in populations that experience health disparities



Community Partnerships to Advance Science for Society (ComPASS)

Lead ICOs: NIMH, NIMHD, NINR, ORWH, (THRO)

Working Group: AoU, CSR, NCI, NCATS, NEI, NHGRI, NHLBI, NIA, NIAMS, NICHD, NIDA, NIDCD, NIDCR, NIDDK, NIEHS, NIMH, NIMHD, NINDS, NINR, NLM, OAR, OBSSR, ODP, ORWH, SGRMO



National Institutes of Health

Office of Strategic Coordination–The Common Fund

What is ComPASS?



- Community Partnerships to Advance Science for Society (ComPASS)
- Supported by the NIH Common Fund
- Health Equity Focus
- Community-Led
- Leveraging Structural Interventions and Multi-Sectoral Partnerships
- Intervening on Social Determinants of Health
- Improve Health Outcomes
- Reduce Health Disparities
- Advance Health Equity Research



Community Partnerships to Advance Science for Society (ComPASS)

To advance the science of health disparities and health equity research, the NIH Common Fund launched the ComPASS Program.

The goals of ComPASS are to:

1. Catalyze, deploy, and evaluate **community-led health equity structural interventions** that leverage partnerships across multiple sectors to reduce health disparities
2. Develop a **new health equity research model** for community-led, multisectoral structural intervention research across NIH and other federal agencies

Program duration: 10 years

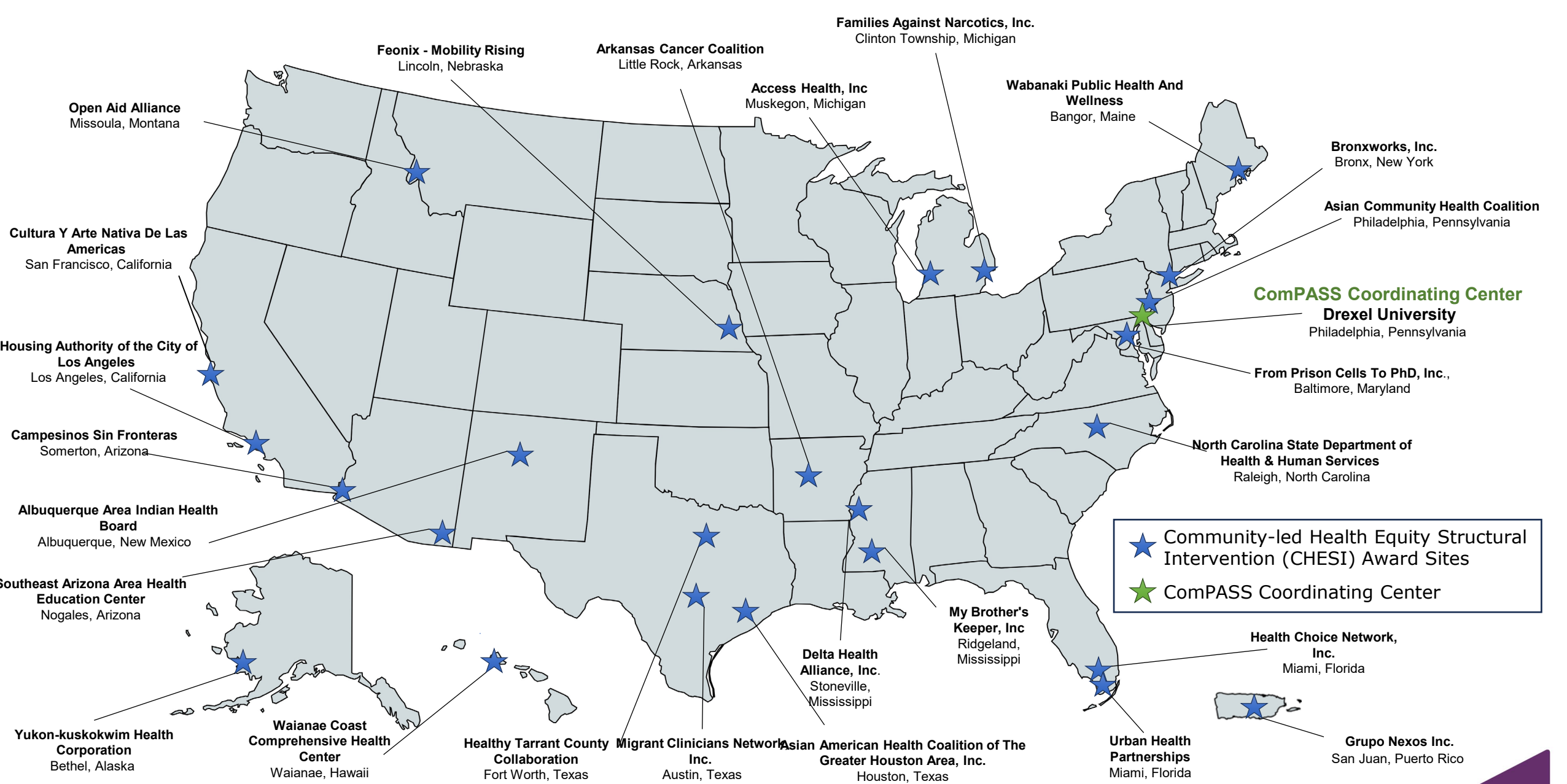
Planned budget: Approximately \$200M in the first five years

ComPASS has three initiatives:



CHESI Awards: Structural Factors





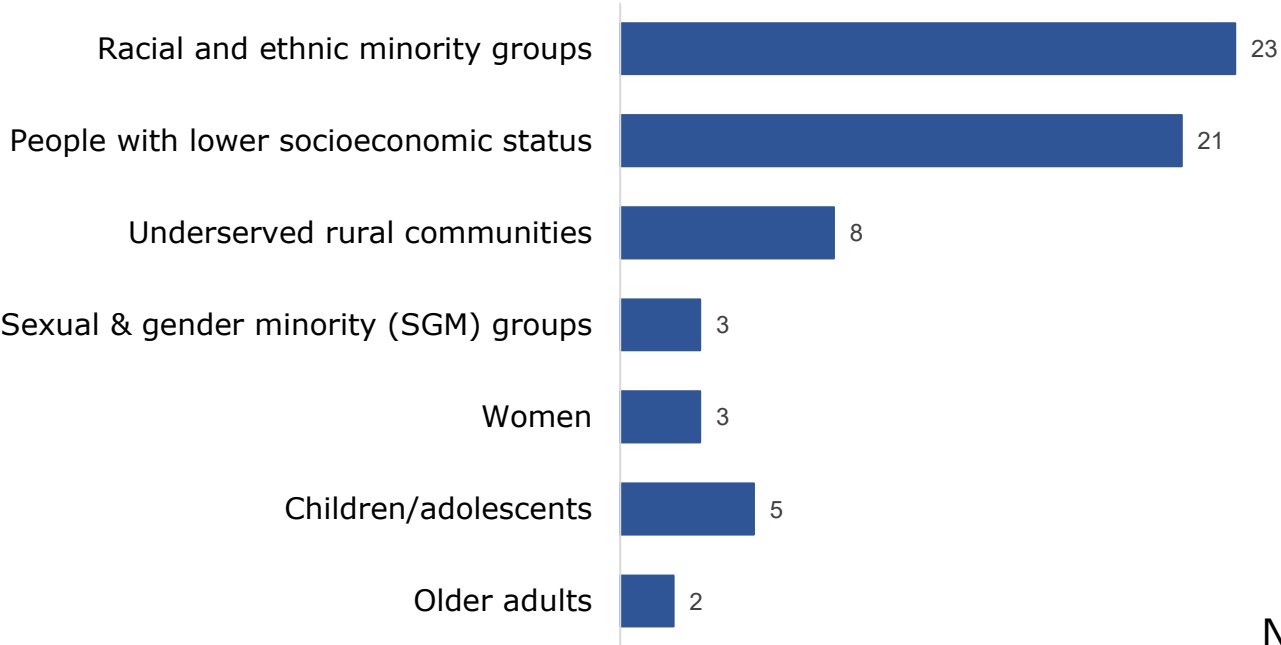
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Community Partnerships to Advance Science for Society Award Sites

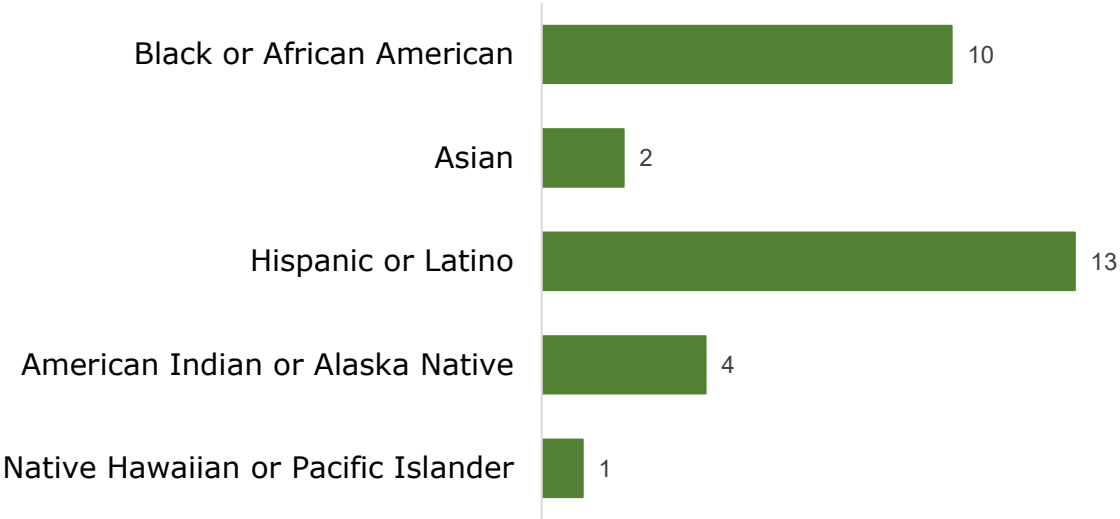


25 Community-Led, Health Equity Structural Interventions: Populations

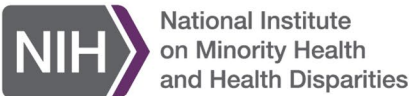
Populations That Experience Health Disparities and Other Populations



Racial and Ethnic Minority Populations



Note: Awards that focus on more than one population experiencing health disparities are included more than once



Community Partnerships to Advance Science for Society (ComPASS) Program Structure

NIH Common Fund, Re-engineering the Research Enterprise (RRE)

Asst. Dir RRE: Cheryl Anne Boyce (OSC)
Program Leader: Cheryl Anne Boyce (OSC)
Scientific Program Analyst: Nikeya Macioce (OSC)

Communications Lead: Sara Amolegbe (OSC)
Business Operations and Analysis Contact: Jason Shockey (OSC)

ComPASS Working Group

Co-Chairs: Janine Austin Clayton (ORWH), Joshua A. Gordon (NIMH), Eliseo J. Pérez-Stable (NIMHD), Shannon N. Zenk (NINR)

Community-Led, Health Equity Structural Interventions (CHESIs)

25 awards

Lead Coordinator: Alison Brown (NHLBI)



POs: Michelle Hamlet (OSC), Margaret Ochocinska (OSC), Susan Shero (OSC), Nadra Tyus (OSC)
PSs: April Oh (NCI), Melissa Smarr (NIEHS), Raquel Greer (NIDDK), Jarrett Johnson (NIMHD), Shahnaz Khan (NHLBI), Lindsey Martin (NIEHS), Madelyn Reyes (NIAID), Minnjuan Fournoy Floyd (NIDA), Jennifer Villatte (NIMH), Angela Holmes (NIDA), Miya Whitaker (ORWH)

ComPASS Coordination Center (CCC)

1 award

Lead Coordinator: Shalanda Bynum (NINR)



POs: Dara Blachman-Demner (NINR-Primary); Nadra Tyus (OSC-Secondary)
Haluk Resat (OSC-Secondary/Data); PSs: Libbey Bowen (NINR) - Administration and Coordination
Grace Peng (NIBIB) - Data Collection, Management, and Assessment
Gniesha Dinwiddie (NIMHD) and Sarika Parasuraman (OBSSR) - Research Capacity-Building and Training

Health Equity Research Hubs (Hubs)

5 awards

Lead Coordinators: Nate Stinson/Crystal Barksdale (NIMHD)



POs: Amanda Acevedo (NCI); Behnoosh Momin (NCI)
PSs: Ebony Madden (NHGRI), Patricia Jones (NIA), Xinzhi Zhang (NHLBI), Tiffany Wallace (NCI)

National Healthy Equity Research Assembly (HERA)

Moving Forward



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Moving Forward

NIH CDE REPOSITORY

- Launched in 2015, provides access to structured human and machine-readable definitions of data elements
- Facilitates interoperability of data



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