

NIH Common Fund's Community Listening Sessions Informing ComPASS: Emerging Themes on Research Gaps and Opportunities

Background:

The NIH Common Fund (CF) launched the Community Partnerships to Advance Science for Society (ComPASS) Program to accelerate the science of health disparities and advance health equity research. The goals of ComPASS are to 1) develop, share, and evaluate community-driven structural health equity interventions that leverage partnerships across multiple sectors to reduce health disparities, and 2) to develop a new health equity research model for community-led, multisectoral structural intervention research across NIH and other federal agencies. In planning for ComPASS, the NIH Common Fund sought input from external communities via a series of listening sessions.

Eight listening sessions during October and November 2021 included representatives from academic institutions; nonprofit/community-based/faith-based organizations; foundations, think tanks, and professional societies; and tribal communities and organizations. Representatives from community, institutional and partner groups discussed research opportunities, challenges, and community needs surrounding interventions that target social factors that influence health and health disparities. A total of 2,100 individuals registered, and over 500 participated across all listening sessions. Below are four themes that emerged across all listening sessions.

Please note that the information below consists of summarized responses submitted by listening session attendees and does not necessarily represent the opinions of the NIH, or the Federal government or necessarily reflect the goals or structure of the ComPASS in its current form.

Community Ownership

Attendees expressed concern that community voices, talents, and lived experiences have historically not been recognized or appreciated during research studies conducted in their communities. Community-focused interventions will enable ownership and research sustainability in collaboration with academic and other partners.

- Increasing transparency about health disparities in research projects will improve the health of individuals and benefit the community.
- Investigators involved in health disparities research should avoid “health equity tourism,” researchers interested in health disparities because current trends often lack a long-term commitment to community engagement and health disparities research ([Lett et al., 2022](#); [MacFarling, 2021](#)).
- Communities want more ownership of research data and the ability to provide input on the research design and how the results are shared.
- Increased representation of underrepresented groups in research leadership positions at NIH are needed.

- Communities affected by health disparities want their lived experiences captured through qualitative research methods, and other related approaches included to enrich the scientific knowledge base

Forging Relationships and Building Trust

Participants emphasized the need for research organizations to build and maintain authentic relationships with communities and community organizations. Specifically, there was discussion around the need for researchers to repair trust in broken relationships with communities and to recognize historical trauma.

- To build trust in communities experiencing health disparities, researchers should start by understanding community partners' needs and meeting people where they are.
- Researchers must devote significant time and effort to gain communities' trust to implement interventions that resonate with the populations of interest and their historical experiences.
- The NIH should have a more visible presence in minority communities. Individuals tend to distrust unfamiliar organizations. Increasing NIH's visibility would improve trust and acceptability of health research and the organizations that conduct it.

Community-Capacity Building

Attendees discussed the need to build community organizations' capacity to effectively develop, implement, and sustain structural interventions and research. These obstacles often interfere with community ownership of health disparities research data and outcomes.

- Most communities and nonprofit organizations are small and lack experience applying for research grant funding and resources. More tools and resources are needed to build research capacity at the community organization level, such as training on research design, how to apply for awards, and managing timelines and budgets.
- Increase awareness of funding opportunities to support research capacity building for community organizations is needed.
- The timeline for NIH funding mechanisms should accommodate the time needed for research capacity building.

Bi-Directional Learning:

Bi-directional learning and mutually beneficial partnerships recognizing community values sustain academic-community partnerships necessary for health equity. Attendees expressed the need to establish bi-directional learning opportunities in which partners collectively engage in discussion and share experiences. Attendees also discussed the need for equitable decision-making and resource allocation to be central to efforts to address upstream determinants of health.

- There is a need for increased accessibility to community engagement training where research investigators, project staff, and community members interact.
- The NIH should invest in community education at the primary and secondary educational levels to expose students to STEM early in life and foster engagement in these careers.

Navigating the NIH Enterprise:

Community organizations, minority-serving institutions, and other low-resourced entities are often disadvantaged in applying for and securing NIH funding. Institutions and organizations underrepresented in NIH funding require assistance navigating the system's complexity.

- NIH funding application cycles with short turnarounds (e.g., as little as one month) can be a challenge for early-career researchers, community partners, and researchers seeking to develop, establish and leverage partnerships for NIH grant submission.
- The NIH should provide grant writing assistance to community organizations and professional societies.
- The NIH can be instrumental in developing opportunities for community organizations to partner with universities on research projects.
- Reducing the complexity of the application process to include forms and system requirements could reduce barriers for community organizations to apply for NIH funding.
- Increase funding for health disparities research across all NIH institutes and centers to ensure that resources are available NIH-wide to stimulate health disparities research applications.
- NIH could create funding opportunities encouraging or requiring comprehensive, collaborative partnerships with community organizations. Connecting community, faith-based, and nonprofit organizations with local public health centers; and facilitating partnerships to strengthen the public health infrastructure can achieve long-term, lasting effects.

NIH Funding Application Review Panels and Process:

Attendees expressed concern about the NIH review process. Attendees discussed how review panels lack racial, ethnic, and gender diversity and often lack the requisite expertise in community-based research and the social and behavioral sciences.

- Reviewers should receive adequate training on community-based research to ensure they are prepared to evaluate community-led research appropriately.
- Attendees noted biases in the review process against underrepresented minority researchers. NIH must ensure that funding doesn't continue to be awarded to the same established researchers and well-resourced institutions.
- NIH should recruit members from community organizations to participate in review panels that have expertise in community-led research. Attendees believe this approach will improve the review process of health-disparities research.

Public-Private Partnerships in Community Health:

Partnerships across multiple sectors, including local, state, and federal governments and community organizations, can be leveraged to support health equity efforts collectively.

- Many successful community interventions are implemented by organizations that form partnerships with community leaders aware of public health issues that influence health and health care systems.

- Community partnerships at smaller, neighborhood scales can help reduce disparities in local communities by addressing social factors that influence health, for example, education and transportation.
- Policy stakeholders should be included in community-led research because they make decisions that impact individuals' health. For example, a one-page policy brief that can be shared with a local politician may be more impactful than a published paper.
- Partnerships with news outlets can combat misinformation and support disseminating accurate, science-based health information.

Data Standardization and Retrieval:

Attendees voiced concerns about community organizations' challenges in leveraging local data sources to inform health equity priorities. The infrastructure to share comparable data across local, state, federal, and private sectors is fragmented. Inconsistencies in data capture across studies limit the ability to build the evidence-base for interventions focused on structural factors that influence health disparities. Furthermore, the lack of standardization in collecting sociodemographic data such as race, ethnicity, gender, and sexual orientation limits the ability to aggregate and pool data across communities.

- The NIH grants could support the building of infrastructure to share data across multiple sectors, including Medicaid or public health data that captures historical patterns and includes people not involved in clinical trials.
- NIH could facilitate training community advocacy groups on city-level data to examine health disparities. For example, how to access data on violence, mental health, and policing practices.
- Many hospitals conduct community health needs assessments in localized areas. The data derived can be used to inform interventions that address health disparities.
- Larger organizations can leverage state-wide resources to study health disparities and address inequities, including education and health care centers.
- Organizations should seek to leverage telehealth data. However, there is a lack of knowledge on the success of telehealth and health services for diverse populations.