UNITE

EXTERNAL LISTENING SESSIONS

EXECUTIVE SUMMARY

NIH National Institutes of Health
Turning Discovery Into Health

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The U Committee of the National Institutes of Health (NIH) UNITE initiative convened listening sessions that engaged multisector audiences from the extramural community (i.e., external to NIH) to listen to and learn from various people's perspectives regarding diversity, equity, inclusion (DEI), and structural racism within the bio-medical research ecosystem. The UNITE initiative, launched in February of 2021, was established to delineate elements that may perpetuate structural racism in the NIH-supported and the greater biomedical research communities, leading to a potential lack of personal inclusiveness, equity, and diversity. The U Committee was charged with **U**nderstanding stakeholder experiences by listening and learning. The external listening sessions were an integral component of the U Committee's work to perform a broad, systematic evaluation to examine the aforementioned topics.

Facilitated by an outside contractor, the listening sessions engaged 1,295 participants from an array of settings in the extramural biomedical community. From December 1, 2021, to February 1, 2022, the U Committee hosted 14 total sessions, each of which was intended to listen and learn from individuals connected to one of the following participant groups:

- Colleges and Universities
- Historically Black Colleges and Universities (HBCUs)
- Nonprofit Organizations (NPOs), Community-Based Organizations (CBOs), and Advocacy Organizations (AOs)
- Minority-Serving Colleges and Universities (MSIs)
- Foundations and Professional Societies
- Research Staff (Assistants, Associates, Technicians)
- Students and Trainees
- Health Centers and Systems
- Tribal Nations and American Indian / Alaska Native Communities
- Faith-Based Organizations and Houses of Worship

The engagement approach included broad outreach via NIH networks, distribution lists, and social media accounts, and direct emails to points of contact within and related to target sectors. Individuals registered via the Eventbrite platform and the sessions were held virtually via Zoom.

To ensure accessibility for people who were deaf or hard of hearing, American Sign Language interpreters par-ticipated in each session and auto captioning was provided. An external facilitator led the sessions, ensuring a safe space for participants, and facilitators provided opportunities for participants to speak and/or provide comments in the chat box.

In this report, the U Committee summarizes the comments provided during the listening sessions to help inform NIH future plans and approaches. These summaries represent the opinions and perspectives of the listening session participants, and do not necessarily reflect the perspectives and practices of NIH.

SUMMARY OF CROSS-CUTTING THEMES IN PARTICIPANTS' COMMENTS

The listening sessions were framed with the context of the well-established socioecological model (SEM) to identify variables across individual, interpersonal, institutional, community, and policy factors. As indicated in the table below, participants described challenges and opportunities regarding:

- The state of equity in the biomedical sciences
- Challenges in career pathways and workforce
- Practices and policies as barriers to equity
- Challenges in health disparities research
- Challenges in addressing health care equity and health outcomes

EXTERNAL LISTENING SESSIONS: CROSS-CUTTING THEMES IN PARTICIPANTS' COMMENTS
State of Equity in the Biomedical Sciences Overall theme of comments: Systemic inequities are perceived as vast across the biomedical research ecosystem • **Disparities in NIH Grant Funding:** Adverse impacts of peer review bias on underrepresented minority (URM) scientists, leading to a lower likelihood of funding • **Micro- and Macroaggressions:** Experiences of discrimination in workplace settings; URM trainees and scientists perceived as less qualified; racial and ethnic minority groups viewed as monolithic • **Disparities in NIH Grant Funding at Minority-Serving Institutions (MSIs):** Adverse impacts of bias against MSIs, Historically Black Colleges and Universities (HBCUs), Hispanic-serving Institutions (HSIs), Predominately Black Institutions (PBIs), and smaller colleges; power differential between Predominantly White Institutions (PWIs) and MSIs disadvantages the latter • **Emerging Issues:** The disproportionate impact of the COVID-19 pandemic among racial and ethnic minority communities laid bare the structural inequities in the health care system

Challenges in Career Pathways and Workforce
Overall theme of comments: Challenges for URM groups begin with primary education and extend throughout secondary education and professional careers
 	
• **Limited Pathways:** Inadequate K-12 STEM education; limited opportunities for URM graduate-level trainees, and challenges in career development and/or advancement among URM faculty members
 	
• **Resource Inequities:** Smaller, less-resourced institutions often lack funds and infrastructure needed to attract and retain trainees and scientists, or to conduct cutting-edge science
 	
• **Lack of Representation and Mentorship Opportunities:**
   o Few role models for youth and early-career scientists (limits entry)
   o Few URM mentors/sponsors (limits advancement)
 	
• **Minority Tax:** URM scientists are often "taxed" with solving DEI problems, providing education around race and ethnicity, detracting from their science, without compensation or recognition

EXTERNAL LISTENING SESSIONS: CROSS-CUTTING THEMES IN PARTICIPANTS' COMMENTS

Practices and Policies as Barriers to Equity

Overall theme of comments: NIH funding structures disadvantage URM scientists and MSIs

- **Complexity in NIH Grant Submission System:** Complicated NIH grant application process creates disadvantages for less-resourced MSIs with limited research infrastructure

- **Bias in Scientific Review:** The lack of racial and ethnic diversity on grant review panels, inconsistent review critiques, and devaluing of health disparities research (often) results in unintentionally biased scoring and funding decisions

- **Bias Toward MSIs/HBCUs**: Perceived inadequacies in MSI/HBCU environment, qualifications; and application requirements that facilitate discrimination and reinforce implicit biases

- **Few Infrastructure Support Opportunities:** Most grant mechanisms exclude resources for infrastructure and capacity-building, and this exclusion facilitates funding inequities

Challenges in Health Disparities Research

Overall theme of comments: There is a need to increase funding for meaningful health disparities research that serves community needs

- **Acontextual Health Disparities Research:** A lack of diversity, limited health disparities expertise ("health disparities tourism"), and lack of cultural knowledge within research teams

- **Need for community-based participatory research (CBPR):** Importance of early and continuous engagement of community collaborators, equitable compensation, and addressing community needs; provide support to ensure sustainability and improve outcomes

- **Data Aggregation:** Combining data from diverse racial and ethnic groups, such as Latino/Hispanic and Asian American and Native Hawaiian/Pacific Islander (AANHPI) populations, presumes subgroups have same needs and obscures between group differences

- **Culturally Incompetent Communication:** Use of complex terminology, not translated into multiple languages, and ineffective patient-clinician communication, reduces inclusion in clinical research

> **EXTERNAL LISTENING SESSIONS: CROSS-CUTTING THEMES IN PARTICIPANTS' COMMENTS**
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> **Challenges in Addressing Health Care Equity and Health Outcomes**
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> Overall theme of comments: Existing barriers and biases reduce the quality of health care and outcomes among racial and ethnic minority patients
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> - **Lack of Patient Advocacy:** The health care system can put the onus of advocacy on the patient, yet community members are often unaware of how to advocate effectively for themselves or others; patient navigation is needed
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> - **Lack of Diverse Representation on Medical Teams:** Racial and ethnic underrepresentation within fields of medicine may deter help-seeking, maintain implicit and explicit biases, and negatively impact health outcomes
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> - **Lack of Cultural Humility:** Medical professionals often lack knowledge about the patients they serve so they may not understand the nuances within communities, historical impacts, and reasons for distrust of health care systems
>
> - **Adverse Social Determinants of Health:** Challenges such as transportation and limited patient access to medication, treatment, and other health-related resources can negatively impact outcomes

The final topics raised by participants focused on actions and initiatives taking place at participant institutions that might serve as examples for improving DEI within the biomedical research community. These actions and initiatives aligned with the four SEM levels and included (individual level) trainings to address cultural competence and implicit bias; (interpersonal level) models for DEI initiatives across settings; (institutional level) actions for inclusion, capacity-building, data collection, and mentorship; and (community level) community engagement for recruitment, relationship-building, and research.

Participants also proposed solutions for NIH—strategies, actions, initiatives, policy changes, and engage-ment methods—to address perceived challenges to DEI within the biomedical research enterprise. The pro-posed solutions were at the institutional and community levels. Institutional-level proposals included increasing accountability for DEI among applicants and grant recipients; modifying application requirements, incentives, and timelines to support capacity-building; cluster hiring and mentorship programs to enhance professional and research pathways among URM scientists, staff, and students; and increased investments in health dis-parities and CBPR. Community-level proposed solutions included data disaggregation within racial and ethnic groups and data sharing to address structural racism, increased visibility of historical and current role models who are underrepresented within the biomedical sciences, and pairing Research 1 (high research activity) and smaller institutions for grant application mentorship in mutually beneficial ways.

A summary of each session is available on the UNITE – Ending Structural Racism website. The external listen-ing sessions complement three other U Committee activities: internal listening sessions and focus groups with the NIH workforce; an internal data call to understand previous, ongoing, and planned DEI efforts across all NIH Institutes and Centers; and a published request for information (RFI) to gather perspectives on approaches NIH can take to advance racial equity within all facets of the biomedical research workforce and expand research to eliminate or lessen health disparities and health inequities. The findings from these activities will be used to inform ongoing UNITE and NIH efforts to address structural racism in the NIH-supported and greater biomedi-cal research community and promote a welcoming environment in the biomedical sciences enterprise.