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July 13, 2015

Eliseo Pérez-Stable, MD
Director
National Institute on Minority Health and Health Disparities (NIMHD)
6707 Democracy Boulevard, Suite 800
Bethesda, MD 20892-5465

RE: NOT-MD-15-006, Request for Information (RFI) Soliciting Input into the NIH Science Vision for Health Disparities Research

Dear Dr. Pérez-Stable,

The Association of American Medical Colleges (AAMC) congratulates the NIH and NIMHD on initiating the process to develop a 10-year scientific vision for the science of health disparities research. We are pleased to have this opportunity to offer comments and suggestions in service of this vision. The AAMC is a not-for-profit association representing all 144 accredited U.S. medical schools, 400 major teaching hospitals and health systems, including 51 Department of Veterans Affairs medical centers, and nearly 90 academic and scientific societies. Through these institutions and organizations, the AAMC represents 148,000 faculty members, 83,000 medical students, 115,000 resident physicians, and thousands of graduate students and post-doctoral trainees in the biomedical sciences.

The United States is a biomedical research innovator. Nevertheless, our nation's population experiences vast and seemingly intransigent inequities in the incidence, prevalence, and prognosis of disease across sociodemographic and socioeconomic groups. This paradox demands the full spectrum of our research enterprise be brought to bear on the development of evidence based policies and interventions to close or mitigate such gaps. Indeed, it is precisely because of its capacity to innovate that the United States must lead the development of solutions to move our nation and the world further along the path toward health and health care equity.

The AAMC reiterates its belief in the importance of NIMHD's effort to develop a cross-Institute and Center (IC), long-term strategic vision for health equity research to create and disseminate solutions to these systematic and avoidable population health differences. We offer our comments across three domains: 1) the causes of health and healthcare inequities; 2) methods and metrics to strengthen our science; and 3) the identification and dissemination of interventions successful at minimizing inequities.

Across all of these domains, the AAMC wishes to emphasize community engagement as an integral component of health equity research as well as any strategic vision, and **we encourage NIMHD to actively engage all communities who suffer from disproportionate morbidity and mortality in the development of the 10-year plan.** While researchers, policy-makers and community leaders have important perspectives that are crucial to include, so too are the voices of individuals who most often bear the brunt of health injustice.

1. Causes of Health and Health Care Inequities

Develop Common Definitions

Foundational to the development of a cross-IC vision for health disparities research are common, guiding definitions of “health disparity/inequity” and “health equity/disparities research”. Without consensus regarding the target of health disparities research, it will be impossible to craft a cohesive vision comprehensive in terms of the outcomes and populations considered to be in scope.

While no explicit definition of “health disparity” is currently provided on NIMHD’s website, it does note, “Many populations in America, whether defined by race, ethnicity, immigrant status, disability, sex, gender, or geography, experience higher rates of certain diseases and more deaths and suffering from them compared with the general population.”

Other ICs offer distinct definitions of “health disparities” on their websites. For example, NIAID focuses on gaps in quality of health or health care that mirror differences in “socioeconomic status, racial and ethnic background, and education level”. NCI’s definition of health disparities populations is more inclusive: “These population groups may be characterized by age, disability, education, ethnicity, gender, geographic location, income, or race.” Finally, NIDA limits its health disparities research to minorities, rural groups, and socioeconomically disadvantaged urban populations. *Of note is the universal exclusion of LGBTQ populations from these definitions.* Given the health and healthcare inequities faced by sexual minorities **AAMC encourages NIMHD to explicitly note LGBTQ populations in their definition of “health disparities” and “health disparities research” alongside other vulnerable populations.**

The AAMC also strongly urges NIMHD to lead an NIH-wide process to develop common definitions of (1) “health disparity/inequity” and (2) “health equity/disparities research” in order to facilitate the development of a unified strategic vision and the evaluation of progress toward the vision’s goals.

Identify Research and Knowledge Gaps

A common definition will also aid in the identification of gaps in NIH’s current and historical health equity research portfolio.

In 2014, AAMC and AcademyHealth released a report on trends in disparities-focused health services research (HSR).¹ We found certain populations – such as persons with disabilities, LGBTQ groups and American Indians/Native Americans – were underrepresented in the disparities-focused HSR portfolio relative to the groups’ size within the US population and the health and health care gaps they experience. Similarly, certain health outcomes particularly amenable to health system intervention – asthma and oral health, for example – were less likely to be represented among funded research projects.

¹ Alberti PM, Kanani NS, Sutton K, Johnson BH, Holve E (2014) “The State of Health Equity Research: Closing Knowledge Gaps to Address Inequities.” Washington, DC: Association of American Medical Colleges.

AAMC suggests NIMHD conduct a similar assessment of the populations and outcomes studied by health equity researchers funded by all NIH ICs over the past decade in order to identify gaps. This analysis can then be cross-walked with epidemiologic data from the Centers for Disease Control and Prevention (CDC) and other sources to better assess the urgency of supporting new research to address groups and health outcomes for which successful interventions are both needed and currently understudied.

2. Methods and Metrics to Strengthen the Science of Health Equity

Promote Community Engagement

Selecting methods and measures for health equity research based on community input and acceptability is a guiding principle for making appropriate choices. Just as various kinds of science – from fundamental discovery to community-based participatory research – can help build the evidence base of solutions to health and health care disparities, various methods and metrics can be deployed in service of health equity research. **AAMC strongly urges NIMHD to require adherence to principles of bidirectional, community engaged research whenever feasible.**

This community input and partnership in research planning can include the identification of acceptable ways to phrase questions, to gather data, to enhance representativeness of study participants, to delineate outcomes of community input, and to develop study designs that include control groups without withholding potentially beneficial treatments from communities who stand the most to gain. Because of NIH's support of community engaged science through NCATS' CTSA program and other funded Centers, literature exists about the most valid ways to conduct and evaluate community-partnered science.² This engagement will not only improve the quality of health equity research, but can also lead to increased enrollment of groups traditionally underrepresented in subject pools, thus extending the research's external validity.

AAMC encourages NIMHD to include in program announcements and requests for proposals the ICs' expectations of community engagement in the development and selection of research questions, study measures and designs, and to develop systems to rate proposals based upon the depth and quality of that engagement.

In addition, AAMC urges NIMHD to ask funding applicants to define and describe explicitly the "community" to be studied and engaged. Common sociodemographic characteristics do not in and of themselves indicate the social cohesion and shared values necessary for a sense of "community" to emerge. The validity and impact of research is likely to increase when communities with a collective sense of norms and understanding – rather than groups merely linked by common skin color or income level – are engaged.

² Eder MM, Carter-Edwards L, Hurd TC, Rumala BB, Wallerstein N. A logic model for community engagement within the Clinical and Translational Science Awards consortium: can we measure what we model? Acad Med. 2013 Oct;88(10) 1430-1436. doi:10.1097/acm.0b013e31829b54ae. PubMed PMID: 23752038; PubMed Central PMCID: PMC3784628.

Align Data across Systems

Health inequities derive from factors at the individual, familial, community and societal levels. A health equity research agenda, therefore, must adopt a systems approach in order to understand causes of inequity and the interactions between those causes.

Given the proliferation of data sets currently available to health equity researchers including (though not limited to) genome-wide association studies, electronic health records and other forms of health information technology, community health needs assessments, and public health data sets, scientists now have tools at their disposal to conduct powerful multi-level analyses to develop and evaluate potential solutions to health and health care gaps. As noted in a recent AAMC comment letter,³ NIH's Precision Medicine Initiative, with its collection of genetic, clinical, social and behavioral data, presents such an opportunity for multi-level, health equity research.

AAMC urges NIMHD to prioritize research that aligns available data streams in ways that allow potential causes and protective factors of inequity to be identified across systems, and that permits analysis of effect modification between variables across these levels.

Incentivize Cross-site Research Collaborations

Key to a systems approach to health equity research methods and metrics is a concomitant focus on contextual variables which influence both the success of an intervention and its initial uptake. Pairing health equity research with implementation science is essential to understand how, once a potentially effective intervention is identified, it can be reliably reproduced in other contexts within other communities.

Cross-site research collaboratives proffer great promise for health equity research as they allow for identification of common, cross-community risk and protective factors as well as site-specific contextual and community-level variables crucial for implementation scientists to consider as they work to transfer evidence based policies and practices to other settings. NIH's Big Data to Knowledge (BD2K) collaborative and the Patient-Centered Outcomes Research Institute's (PCORI) PCORnet are cutting-edge examples of currently funded efforts to realize the potential of linking centers and data across the United States in support of improved patient and population health.

The NIMHD should incentivize collaboration between its currently funded Centers of Excellence for Disparities Research and other equity-focused IC-funded Centers in order to maximize the identification, transfer and implementation of strategies to mitigate health and health care inequities.

3. Identifying and Disseminating Effective Interventions to Minimize Inequities

Support Evaluation Science

³ AAMC Comment Letter, June 19, 2015, available at:

<https://www.aamc.org/download/435116/data/aamcsubmitsacommentlettertonihonpmiandcommunityengagement.pdf>

In order to identify program and policy interventions effective at minimizing or closing health and health care gaps, formal evaluations are required. However, funding for evaluation and intervention research is scarce, as is a workforce experienced in evaluation science. Additionally, an evaluated intervention found to be effective in one context will, in some way, require adaptation to other contexts and communities potentially jeopardizing its initial effectiveness. **AAMC strongly urges NIMHD to work with the other ICs to provide funding for health equity research focused on implementation and evaluation of potential solutions to health inequities.**

Community engagement is key to evaluation science, and working with local populations at every stage – from crafting the intervention, to determining important clinical and community outcomes, to creating data collection strategies – is essential. Policy and program interventions are more likely to be oriented toward success when developed with communities who stand to benefit the most.

AAMC encourages NIH to fund community-partnered evaluation and replication studies that not only assess short-, intermediate- and long-term outcomes, but include both formative and process evaluations so that considerations related to intervention development and implementation are well-documented and available to future teams of scientists and evaluators.

Additionally, given the reciprocal nature of community engaged and partnered science, **AAMC suggests that NIMHD and the other ICs fund science that evaluates benefits that accrue to both communities and to their academic research partners.** Measuring the extent to which community engaged scholarship impacts the culture and climate of academic research partners in terms of their ability to effectively communicate with, respect, and meet the needs of the populations they serve are important outcomes of health equity research that should be documented and disseminated.

Leverage existing resources across federal agencies

As the evidence base of effective and replicable interventions targeting health inequities continues to grow, communication between federal agencies will be crucial to disseminate effective programs and policies from one entity to another. **Coordinating funding opportunities between ICs as well as other HHS funding stakeholders like CDC, HRSA and AHRQ will assure that all elements of health equity research – from fundamental discovery to public health research to workforce studies – are complementary and feed into a comprehensive, national strategic vision.**

In addition, the CDC has developed a “Community Health Improvement Navigator” which, in part, acts as a database for tested and effective interventions. As funded science begins to yield fruit in terms of evidence based program and policy interventions, NIMHD should work with CDC so results of intervention and evaluation science are rapidly assimilated into the Navigator. Similar processes for sharing results of program evaluation could be developed for other federal funders as well.

AAMC suggests that the NIMHD’s 10-year strategic vision include clear processes for inter-IC and inter-agency communication, coordination and information sharing so that the burgeoning evidence base of solutions can be shared and spread.

Broadly Disseminate Results

Many stakeholder groups are invested in health equity research. Researchers, communities, health system administrators, public health agencies, local and state legislators, patients and others care deeply about determining which programs and policies are effective at minimizing or eradicating inequities in health and health care. However, the metrics that matter to these groups differ: while communities might care most about population health outcomes, health systems might value system efficiencies while legislators focus on neighborhood economic impacts. Assuring that health equity-focused evaluation science incorporates outcomes salient for multiple groups is a first step. Disseminating pertinent outcome information to those groups in effective ways is the second.

AAMC urges NIH and NIMHD to engage a large number of diverse stakeholder groups to determine how to communicate the results of health equity research in ways that increase the likelihood of adoption and implementation of evidence based strategies. In addition, NIH might consider including a 'Dissemination Strategy' section in their RFPs to ensure that investigators consider their audiences and the outcomes - as well as the communication channels - that matter for those audiences. NIH might also engage PCORI to understand how its AHRQ-assisted dissemination strategy has increased communication and adoption of research findings.

The development of a long-term strategic vision for NIH-funded health equity research is an important endeavor and AAMC appreciates the opportunity to submit comments and suggestions. We would be pleased to work with the NIH and NIMHD to advance this initiative. Please contact me or my colleague Philip M. Alberti, Ph.D. (palberti@aamc.org) with any questions about these comments.

Sincerely,

A handwritten signature in blue ink that reads "Ann Bonham". The signature is fluid and cursive, with the first name "Ann" and last name "Bonham" clearly legible.

Ann C. Bonham, Ph.D.
AAMC Chief Scientific Officer