AcademyHealth

July 31, 2015

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National Institute on Minority Health and Health Disparities
National Institutes of Health
6707 Democracy Blvd. Suite 800
Bethesda, MD 20892-5465

Re: Response to RFI Soliciting Input into the NIH Science Vision for Health Disparities Research

Dear Dr. Dankwa-Mullan:

AcademyHealth welcomes the opportunity to provide input to the National Institute on Minority Health and Health Disparities (NIMHD) on the National Institutes of Health (NIH) Science Vision for Health Disparities. We are the professional home of more than 5,000 health services researchers, policy experts, and practitioners, and we support the production and use of evidence to inform policy and practice. Our Disparities Interest Group has more than 800 members who inform the field by sharing knowledge, challenges, methods, and best practices in addressing inequities in health care access, quality of care, and health outcomes.

The request for information is an important indicator that NIMHD seeks to engage a broad array of stakeholders to help create a transformational agenda for the science of health disparities. While it is important to work with the NIH-funded research community to identify research gaps and priority areas for translational efforts to reduce and eliminate disparities, we are pleased that NIMHD plans to take a broad view of the multiple factors that intersect in the daily lives of health disparity populations to affect health and access to health care.

There are many dimensions to health and health care disparities, and although we have made progress in addressing some of these, much remains to be done. The science of health disparities must help society better understand the many contributing factors to health and health care disparities, including social, ecological, environmental, socioeconomic, and biological factors, as well as the numerous types of disparities that exist today: disparities related to race, ethnicity, gender, disability, geography, and sexual orientation.

One of the strategies that the Institute is pursuing to achieve its mission and that supports all the questions listed below is promoting the diversity of the research workforce. This is a critically important goal in and of itself, as a research workforce that includes and represents the rich diversity of this country will support a robust, innovative, and responsive science enterprise. Diversity of the workforce, particularly racial and ethnic diversity, has also been identified as contributing to a strong disparities research portfolio. NIMHD should assess the range and reach

of its current workforce programs and ensure that they are supporting both individual and institutional programs to recruit, train, mentor, and retain a diverse workforce.

The Institute's questions appropriately span the full continuum of science that is needed to address health disparities, however our comments emphasize priorities in questions 2, 3 and 4, as we believe that significantly more has already been accomplished in understanding the scope, nature, and causes of health and health care disparities, and that it is vitally important to move existing evidence into action and to approach remaining questions in new, highly collaborative ways.

Question 1: Causes of Health Disparities

As noted above, much has been learned about the multiple factors that individually and collectively contribute to health disparities. However, how much is known about etiology and causal factors varies by the type of disparity being studied as well as the complex interactions between various causal factors.

For example, as genomic and other advances accelerate our ability to develop and use precision medicine, it is also necessary to understand the interactions between biology and social, environmental, and other external factors so that this can inform the development of prevention and treatment interventions.

At the same time, advances in genomics, proteomics, and epigenetics raise numerous ethical issues which, in the context of health disparity populations, could lead to misuse or unintended consequences which worsen health disparities.

Question 2: Best Methods, Measures, and Approaches to Advance Health Disparities Science

Over more than two decades a tremendous amount of work has been done to identify standard indicators of community health, both to set population health goals and to help benchmark progress toward those goals. For example, the *Healthy People 2020* national health promotion and disease prevention goals have framed the national agenda and include more than 1,200 objectives to monitor and improve population health both by developing new indicators and defining existing measures. Public reporting on disparities has been done for more than 12 years by the Agency for Healthcare Research and Quality (AHRQ), focusing on the role of health care access and quality in improving community health. The Health Indicators Warehouse (http://www.healthindicators.gov/) provides direct access to a user-friendly, single source for national, state, and local health indicators, and the County Health Rankings (http://www.countyhealthrankings.org/) provides data visualizations that can be used by community groups.

But even with the wealth of existing resources and the number of indicators from which to choose, there are a number of serious limitations in measures that can address health disparities. For example, the National Quality Forum has included a focus on health and health care

disparities and population health, but a significant need exists to develop more granular population health measures and to identify measures of health disparities that are actionable at the delivery system level. This is an important gap. New indicators are needed for measuring the performance of health systems' response to the health and health care needs of disparity populations.

Measures and data related to sexual orientation, gender identity, and disability are both limited and poorly understood, and would be valuable to both the disparities research and delivery system communities. Another important limitation of our existing measures is that the most granular measures available are at the county level, only rarely at the zip code level, and almost never at the level of a neighborhood or community. They do not measure the quality of life and access to resources within an immediate environment – e.g., proximity of fresh, affordable vegetables or exposure to air pollution – nor do they address issues of social cohesiveness, social isolation, or community resiliency.

Similarly, electronic health records provide a wealth of personal health information but these data lack context about where the person lives, works, plays, prays, and socializes. Thus, it is very difficult to translate all this new data into tailored, effective prevention strategies or early interventions. In addition, there are many, nontraditional sources of data, including those from social media, personal health information from mobile devices, and consumer purchasing behavior which provide a 'digital footprint' that could be utilized to create better, customized health care based on individuals' behaviors and lifestyles.

We suggest that NIMHD consider ways to strengthen available data that would support more detailed analysis of the interactions between neighborhoods, people's needs, health care, and health. In this regard, we are encouraged by work being done in the emerging field of geomedicine, where new data tools, such as GIS (geographic information system) software can identify neighborhoods with higher proportions of asthmatics or COPD patients and target mobile vans and other outreach methods to those areas. We are similarly encouraged by some of the collaborative work done by public health and housing authorities, where asthma admission rates can be reduced by improving the quality of housing, buying air conditioners to filter polluted air, and other low-cost interventions that make sense from a systems perspective. In addition, there are local entities and community groups, such as neighborhood planning units, that collect information on their units and could provide greater insight into more closely-knit groups. For example, in Atlanta, there are neighborhood planning units that collect information specifically related to those units, defined by fairly small neighborhoods that have unique structural characteristics, such as roadways or highways that influence health and health care access. Therefore, NIMHD may want to learn about innovations occurring in communities related to data collection and measurement, as local areas have their own way of measuring information.

We recognize that these interventions are not primarily clinical, but the available evidence strongly suggests that more community-based benchmarks and programming are essential to reduce disparities in access and health status for a wide variety of chronic health conditions. We

therefore suggest that a core set of neighborhood-level indicators be developed for defining and tracking progress in reducing disparities.

Question 3: Promising Practice and Policy Interventions

Whether using the frameworks and terminology of "social determinants of health," "environmental determinants," or "intersectionality theory," we believe a systems perspective is needed to appreciate and address the health problems created by resource inequities, discriminatory practices, and institutional bias and racism. Thus, NIMHD deliberations may be informed by including researchers and policy experts in housing, education, employment, transportation, urban planning, criminal justice, banking, and other fields that have a direct impact on the lived experiences of disparity populations and in particular communities of color.

It is important to also recognize, evaluate, and leverage the tremendous transformation that is taking place in health care delivery due to both Affordable Care Act implementation and market forces to address health and health care disparities. For example, an increasing emphasis on population health accountability is leading to innovative delivery system strategies to move health care "upstream" to address social determinants of health. Payment innovations are changing how providers are incentivized, penalized, and/or rewarded. Any of these individually or in combination could affect existing health disparities in either positive, intended ways or lead to unintended consequences and worsening disparities. NIMHD has an important role to play in studying these interventions and generating the crucial evidence on their impact on health disparities. In doing so, the Institute should build on their existing collaboration with AHRQ and further develop innovative methods for evaluating complex interventions that balance rigor, timeliness, and relevance. In addition, NIMHD should develop innovative partnerships with a full range of public and private sector organizations, including health care delivery systems and public health agencies.

As NIMHD advises the NIH science vision for health disparities, we urge it to prioritize health services and systems research as a crucial component in the continuum of health research. In particular, we believe that the body of work being generated by Community Engaged Research, including Community-Based Participatory Research (CBPR), as promoted by the NIH Office of Behavioral and Social Sciences Research (OBSSR) and many other NIH components, is an extremely valuable way to produce evidence that can be applied directly to improve population health and reduce disparities. This highly collaborative approach provides a best practice for engaging partners with different expertise and areas of interest to identify shared problems that can be addressed by developing actionable solutions that all parties can agree to.

Finally, other Institutes have had a significant impact on improved health by generating the evidence base on the role of policy interventions such as tobacco-related policy. NIMHD's vision for the science of health disparities should include a focus on studies of policy interventions at the national, state, and local levels and their distributional impacts on health disparities. For instance, the disproportionate impact of obesity in low income and racial/ethnic minority communities is significant, and the evidence is still lacking on which policies (e.g.,

calorie labeling, violence prevention, taxes) are most effective at promoting healthier behaviors for which populations.

Question 4: Effective Dissemination and Implementation Science Approaches

Dissemination and Implementation Science seeks to promote and rigorously evaluate strategies for integrating evidence-based approaches into clinical and diverse community settings via public health practice, health care delivery, and health care policy. It is therefore a critically important dimension of science to addressing health and health care disparities.

While we have suggested that NIMHD broaden its consideration of more areas of expertise and different communities, evidence shows that dissemination strategies, including messaging, need to be targeted to their audience to be effective. Standards of practice in the communications field, many of which were pioneered at NIH by the authors of the well-known NCI "pink book" (http://www.cancer.gov/publications/health-communication/pink-book.pdf) already incorporate an evidence-based, collaborative approach that focuses on knowing one's audience and using the language and media channels that are preferred by the target audience.

As NIMHD crafts its vision for the dissemination of its findings it will also be important for the Institute to put new findings into context of the existing body of evidence for end users, the public, the media, and policymakers. In other words, to better make use of their contributions, new developments, discoveries, and advancements should be explained in light of existing evidence—helping people understand where the new work fits among what is known and unknown.

As still emerging fields, the definitions of dissemination and implementation and the type of research they encompass may vary according to setting, sponsor, mechanisms of action, and target. The intent of this research is to investigate and address social, behavioral, economic, and organizational factors and policies that impede effective dissemination and implementation of evidence-based clinical, public health, and organizational findings, test new approaches to improve health programming, and determine causal relationships between the strategies to implement interventions and the impacts of their use.

Dissemination and Implementation Science is also characterized by a focus on variations in dissemination and implementation processes (e.g., how evidence/interventions are integrated) and how the context (e.g., setting, population, and economic drivers) leads to heterogeneity of results. Implementation Science can further maximize these dissemination methods by revealing which ones can be replicated or even expanded, increasing in scale when the evidence warrants it.

In AcademyHealth's work with the Electronic Data Methods Forum, the Patient-Centered Outcomes Research Network, and other networks, we have found that communities of practice are often more open to dissemination of information about innovative methods, practices, and measures after they have developed a sense of shared challenges from the current approaches and appreciate the value of collaboration, rather than viewing each other as competitors. We believe

it would be extremely valuable to have a better understanding of the actors and processes that help communities to accelerate collaborative interventions that address longstanding problems from a new perspective.

Summary

We look forward to working with NIMHD to determine how best to integrate the health services, public health systems, and implementation science communities into the science visioning deliberations.

If you have any questions about these comments, please don't hesitate to contact Dr. Lisa Simpson, President & CEO of AcademyHealth, at 202.292.6747 or lisa.simpson@academyhealth.org.