

July 28, 2015

Re: NOT-MD-15-00

Yvonne T. Maddox, Ph.D.
Acting Director, National Institute on Minority Health and Health Disparities
National Institutes of Health
6707 Democracy Boulevard, Suite 800
Bethesda, MD 20892-5465

Dear Dr. Maddox,

The Endocrine Society appreciates the opportunity to comment on the National Institutes of Health (NIH) Science Vision for Health Disparities Research. We fully support the mission of the National Institute of Minority Health and Health Disparities (NIMHD) to “promote and support research to improve minority health and eliminate health disparities” and we anticipate that the Science Vision will serve as an instrumental guide for researchers.

Founded in 1916, the Endocrine Society is the world’s oldest, largest, and most active organization dedicated to research on hormones and the clinical practice of endocrinology. Our membership of over 18,000 includes many of the world’s experts on health disparities in endocrine disorders. To support NIMHD in the development of the Science Vision, our response highlights recent scientific advances that should be prioritized by NIH, infrastructure and resource needs for researchers, and new policies to promote effective interventions. A complete review of the necessary endocrine-focused research questions that should be addressed by a science vision is beyond the scope of this letter. We therefore encourage NIMHD to also examine the detailed recommendations and gaps in knowledge described in the Endocrine Society’s Scientific Statement on Health Disparities in Endocrine Disorders¹.

Infrastructure and Resources

Teams working in resource-limited environments frequently face barriers accessing populations and providing care to research participants. Collaboration and cost-effective approaches are necessary elements of infrastructure to support research and reduce health disparities. NIH should therefore explore models to broadly disseminate or implement strategies from prior research programs that have already identified best practices and opportunities.

Furthermore, for financial reasons or time constraints, underserved populations may not have access to centers of excellence with expertise in a specific condition. It will therefore be important to support research to evaluate access by underserved populations to specialty centers, and assess infrastructure models that enable highly-trained physicians to practice in

¹ Golden, S.H. et al., [Health Disparities in Endocrine Disorders: Biological, Clinical, and Nonclinical Factors – An Endocrine Society Scientific Statement](#). *J Clin Endocrinol Metab* 2012. 97:E1579-E1639



these communities. For example, NIH-funded research could identify unexplored opportunities in telemedicine or models of distributed learning and care, such as training in unconscious bias.

Finally, technological change can be a transformative agent in healthcare. However, uptake and access to new technologies may introduce new disparities or worsen existing disparities². As the pace of technological change accelerates globally, new technologies such as electronic medical records will need to include ethnicity-specific templates to help physicians recommend and deliver patient-focused interventions that consider cultural differences and environmental barriers. It will be critical to conduct research to understand why new technologies are more or less effective, and what commonalities enable successful implementation and dissemination of effective technology.

To address infrastructure and resource issues as part of the Science Vision, we encourage NIH to:

- Increase support for mechanisms to connect community centers that use effective methods for addressing health disparities
- Explore models for sharing successful programs, and support research to determine why some programs are less successful and how they can be modified
- Support research on implementation science, specifically how to deliver effective methods at lower cost and to various underserved communities and settings
- Invest in efforts to improve utilization of technologies in underserved communities; support research to understand why applications succeed or fail
- Fund the development and testing of ethnicity specific templates to learn whether physicians can achieve patient focused outcomes by considering cultural differences and environmental barriers

Scientific Advances That Should Be Prioritized

While the Scientific Statement referenced above represents a broad summary of research gaps and important scientific advances relevant to endocrine-related health disparities, we identify here several additional cross-cutting scientific themes that should be prioritized in the Science Vision.

We stress that translational and outcomes-focused research should be a central theme of the vision. Interventions should be tailored to specific populations, and studies need to be conducted in, and designed for application in real-world settings such as outpatient clinics, prisons, and schools. Outcomes-focused research on training programs that incorporate cultural competency training, or implement technology and telemedicine training, could also identify cost-effective training modules that could be broadly disseminated. We are therefore

² Sequist, Thomas D., Health Information Technology and Disparities in Quality of Care. *J Gen Intern Med*. 2011 Oct; 26(10): 1084–1085.



encouraged that NIMHD has issued an additional RFI on interdisciplinary training in health disparities science³.

There currently exist many potential interventions that might reduce disparities. However, there are few data from comparative effectiveness research comparing interventions in different settings, varied populations, or alternative providers such as patient navigators and community health workers. Testing interventions in subpopulations with different genetic backgrounds may prove to have a positive effect on reducing disparities.

The Science Vision should also highlight how health disparities persist from pediatrics through the transition to adult care. Many young patients in the United States medical system are undocumented, have inconsistent access to healthcare, and face disparities as a result. For chronic diseases such as diabetes, the transition to adult care is particularly challenging, and taking ethnicity into account adds complexity.

In summary, we recommend that the following scientific areas be prioritized in the Science Vision:

- Translational and outcomes-focused research in real-world settings
- Continued research on the benefits of community health workers and advisors
- Pediatrics and transitions of care, especially for chronic diseases
- Evaluation and comparison of training models, including new models identified through responses to NOT-MD-15-014

Policy Considerations

The Endocrine Society agrees that barriers to effective care can be reduced by policy changes. However, policies must be subject to monitoring systems and additional research to ensure that new policies are cost-effective, have the desired effect, and can be implemented in real-world settings. As noted earlier, there is a critical need for effective policies to increase access to care and treatment centers for those in low and middle income areas. Educational efforts are also needed to encourage individuals to seek medical help when needed. Finally, the changing healthcare landscape in the United States offers opportunities and challenges for the reduction of healthcare disparities. Research on affordability and increased portability of insurance will be central to the effectiveness of any policies to reduce health disparities.

We applaud the announcement of the new NIH policy on the consideration of sex as a biological variable in preclinical research⁴⁵. We believe that an NIH Science Vision on Health Disparities Research should reflect the need to study sex and gender disparities, and how they vary across ethnic groups, as a cross-cutting theme. For example, ensuring that the results of

³ <http://grants.nih.gov/grants/guide/notice-files/NOT-MD-15-014.html> Accessed July 17, 2015

⁴ <http://grants.nih.gov/grants/guide/notice-files/NOT-OD-15-102.html> Accessed July 17, 2015

⁵ [Endocrine Society Comments to NIH RFI on the Consideration of Sex as a Biological Variable in Research](#) Accessed July 17, 2015



research on health disparities are disaggregated by sex/gender could help researchers identify previously unknown sex differences, and guide additional research in cell and animal models that includes both males and females.

Therefore, to ensure that the Science Vision guides research that will inform effective policy solutions, we recommend that the Vision:

- Prioritize research that will identify and promote standards of insurance affordability and portability as a means to effective care.
- Identify opportunities to work with the NIH Office of Research on Women's Health to advance the science of health disparities by analyzing data on biological sex and gender across different ethnic groups.

In Conclusion

The Endocrine Society recognizes the need articulated in the RFI notice to “promote and support research, research training, capacity-building, and outreach dissemination” for minority health and health disparities and we anticipate that the Science Vision will prove to be an effective tool to reduce health disparities in the coming decade. We hope that our comments are helpful as you develop the Science Vision and we look forward to working with NIMHD and NIH to develop and implement a transformational approach to understanding the causes of health disparities and reducing their impact. Thank you for considering the Endocrine Society's comments. If we can be of any assistance in your efforts, please do not hesitate to contact Dr. Joseph Laakso, Associate Director of Science Policy at jlaakso@endocrine.org.

Sincerely,

Lisa Fish, MD
President
Endocrine Society