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Dr. Mark Pitcher
National Center for Complementary and Integrative Health (NCCIH)
9000 Rockville Pike
Bethesda, Maryland 20892

*Cover letter submitted electronically to WPHFramework@mail.nih.gov
Responses submitted via webform*

Re: Request for Information (RFI): Identification of a Set of Determinants for Whole Person Health [Notice Number: NOT-AT-22-019]

The Association of American Medical Colleges (AAMC) Center for Health Justice (“the Center”) appreciates the opportunity to provide comments on the NCCIH’s plans to define a set of key determinants that addresses all aspects of the “whole person health model,” including the factors and determinants that positively or negatively impact the full continuum of health. We strongly support Federal efforts to standardize the collection of data, including minimizing actual and potential barriers (e.g., policies, regulations, activities) that present challenges to addressing social determinants of health and sharing health-related information.

The AAMC is a nonprofit association dedicated to improving the health of people everywhere through medical education, health care, medical research, and community collaborations. Its members comprise all 155 accredited U.S. and 16 accredited Canadian medical schools; approximately 400 teaching hospitals and health systems, including Department of Veterans Affairs medical centers; and more than 70 academic societies. Through these institutions and organizations, the AAMC leads and serves America’s medical schools and teaching hospitals and the millions of individuals employed across academic medicine, including more than 191,000 full-time faculty members, 95,000 medical students, 149,000 resident physicians, and 60,000 graduate students and postdoctoral researchers in the biomedical sciences. In 2022, the Association of Academic Health Centers and the Association of Academic Health Centers International merged into the AAMC, broadening the AAMC’s U.S. membership and expanding its reach to international academic health centers. Learn more at aamc.org.

The AAMC Center for Health Justice was founded in 2021 with the primary goal for all communities to have an equitable opportunity to thrive — a goal that reaches well beyond medical care. Achieving health justice means addressing the common roots of injustice through implementation of policies and practices that are explicitly oriented toward equity. The AAMC Center for Health Justice partners with public health and community-based organizations, government and health care entities, the private sector, community leaders, and community members to build a case for health justice through research, analysis, and expertise. Additional information available at www.aamc.org/healthjustice.

As requested by the NCCIH, the Center submitted a response to this RFI in the required webform. However, the 12 determinants with the corresponding MeSH terms that the Center chose to enter into the webform, do *not* represent a comprehensive set of determinants for whole person health, but those that

were identified through the exercise described below as having particular importance or as being routinely overlooked in policymaking efforts. The purpose of this letter is to provide the NCCIH with additional context for our response, including recommendations on how the responses to this RFI could be considered as the NCCIH is forming next steps.

Solicitation of Responses

Through a series of email invitations, groups of individuals from across the AAMC and the Center community were encouraged to complete a short questionnaire to provide perspectives on some key factors and determinants that could be used in research and patient care in support of the full continuum of health. Although the questionnaire also included information to allow individuals to respond to the NCCIH RFI directly, the Center used this “crowdsourcing” exercise to inform its response.

Respondents were asked to identify social determinants that have the most significant impact on health or the progression of disease, select determinants they believed had the most impact on health from a list, and provide the Center with other determinants that they felt are neglected or under-addressed in research or policymaking.

Recipients of the invitation included all AAMC employees and the AAMC Center for Health Justice community partner network, *AAMC Collaborative for Health Equity: Act, Research, Generate Evidence* (CHARGE). CHARGE is a collective of academic health centers and their multisector community partners that work together to advance research, policy, and programmatic solutions to health and health inequities.¹ Central to the mission of the Center is authentic community engagement to advance equity, civil rights, racial justice, and equal opportunity. The CHARGE community is an important part of this mission, and the expertise from this community has served as an indelible resource for the Center’s programmatic activities, responses to proposed policy and regulation, and congressional requests. Given that CHARGE’s work impacts many areas of the research enterprise (e.g., institutional, state, local, and federal levels) and touches on a vast range of determinants of health and other factors, we believed this group was in a unique position to provide feedback on this activity.

Further, the Center’s interest in sharing this RFI with the AAMC and Center stakeholder and partner community was also to ensure this information reached individuals and groups that might be unaware of important comment opportunities proffered by the Federal Register or the NIH Guide Notice for Grants and Contracts such as this one. Considering, the NCCIH’s efforts to develop a comprehensive set of social determinants should not end with this request. As discussed briefly below, we encourage additional opportunities for bi-directional community input, including the establishment of community working groups and working directly with community-based organizations to gather on the ground wisdom and perspective on the development, implementation, and retrospective evaluation of activities related to this RFI.²

¹ See, AAMC Center for Health Justice, *CHARGE*, <https://www.aamchealthjustice.org/get-involved/aamc-charge> (last visited June 13, 2022).

² For ways the NCCIH can build meaningful community patronships, see: AAMC Center for Health Justice, <https://www.aamc.org/healthjustice>; Also see, *AAMC Principles of Trustworthiness*, <https://www.aamc.org/trustworthiness>, *Principles of Trustworthiness Toolkit*, <https://www.aamc.org/trustworthiness#toolkit>; *AAMC Community Engagement Tool*, <https://www.aamc.org/what-we-do/mission-areas/medical-research/healthequity/community-engagement/toolkits> (last visited June 15, 2022).

Notable Outcomes from the Questionnaire

The Center received 67 responses to the questionnaire and used those responses to inform the Center's response to this RFI as further described below.

Factors that Impact Social Determinants of Health

In an open-ended question asking for key factors that come to mind when thinking about social determinants of health, 60% of the 67 respondents reported neighborhood and public safety as a key determinant. Education, economic stability, and food security were listed as other common determinants by respondents (57%, 37%, and 37%, respectively).

Commonly Referenced Determinants that have a Significant Impact on Health or the Progression of Disease

Respondents were provided a list of eight commonly referenced determinants (racism and discrimination, housing, transportation, neighborhood and environment, food security, economic stability, education, and the health care system) and asked which had the most significant impacts on health, choosing as many of the eight as they wanted. 81% of respondents selected economic stability as a determinant that significantly impacts health, 75% selected racism and discrimination, and 69% selected neighborhood and environment.

Other Determinants that are Neglected or Under-addressed in Research or Policymaking

In an open-ended question asking respondents to list any determinants they believe are neglected or under-addressed, many respondents who provided determinants reported mental health (46%), social isolation (27%), policing and incarceration (27%), and climate change (22%) as determinants that are neglected or under-addressed in research or policymaking.

Observations and Recommendations

Definition Challenges and Comprehensive Understanding of Social, Structural, and Cultural Context

Evident from the findings is the notable variation in how respondents interpreted the meanings associated with certain factors and social determinants. For example, in the first open-ended question, only 51% of respondents identified economic stability as a key factor impacting health and the progression of disease. However, in the question immediately following that provided a list of common determinants (see list above), a sizeable majority of respondents (81%) selected economic stability as a determinant with a notable impact on health and disease progression. While all respondents were provided with a baseline definition of "social determinants of health,"³ there appear to be discrepancies in how factors and determinants are defined on an individual basis. For example, several respondents identified demographic information (i.e., race, sexuality, and religion) as a social determinant. However, demographics are descriptive characteristics of a population, and do not define overarching determinants of health like racism or homophobia.

In the RFI, the NCCIH notes that it is limiting the number of determinants each commenter can submit "to ensure a list sufficiently comprehensive to capture the key elements of whole person health." Efforts to comprehensively capture *key elements* of health must also account for how these elements interact with

³ See, the Department of Health and Human Services, Office of Disease Prevention and Health Promotion, Health People 2030, definition of "Social determinants of health (SDOH) are the conditions in the environments where people are born, live, learn, work, play, worship, and age that affect a wide range of health, functioning, and quality-of-life outcomes and risks." *Id.*

other determinants, especially when the consequence of these interactions could produce new or exacerbate existing inequities. Further, while the definitional challenges identified above help to underscore the importance of the NCCIH’s efforts to define a “common list of determinants,” they also highlight the need for a more comprehensive understanding of additional issues that NCCIH should consider to meaningfully and successfully operationalize this initiative:

- Harmonized understanding of the definitions/context associated with each identified factor/determinant (e.g., individual, social, structural, genetic, etc.), not just identification of the terminology itself.
- To enhance standardization and data collection efforts, standard taxonomy should include terms that are often (and erroneously) used interchangeably. For example, the AAMC, the Center for Health Justice, US Centers for Disease Control and Prevent, World Health Organization and others define social determinants of health (at the community level) as factors that exist in places where people are born, live, work, and play. As the Center noted in a 2021 letter to the *Congressional Social Determinants of Health Caucus*, “[t]he maldistribution of SDOH across communities puts individuals within adversely affected communities at *social risk*, risk that may turn into a *health-related social need* (HRSN) for individuals (for example, housing instability or homelessness resulting from the lack of community-level affordable housing).”⁴
- Need for interoperable communication across differing technology platforms, including addressing lack of access to technology/broadband and financial resources.⁵

Federal Government Coordination and Community Engagement

We do not want to minimize the ambitious and commendable undertaking to identify a common set of determinants for use in research and patient care, but would like to respectfully emphasize the need for the NIH in partnership with the NCCIH, to prioritize a coordinated *whole-of-government* approach, expanding this initiative far beyond the NIH-NCCIH to other Federal and state agencies doing this work. For example, the Center held a congressional briefing, “[Data for Health Equity: the Foundation for Creating Healthier Communities](#)” which noted that one key barrier impacting all communities is the lack of coordination between relevant sectors— housing, public health, medicine, transportation. Notably, it also highlighted the similar data needs related to demographics, individual-level social needs, and community-level social determinants, among others.⁶

It is notable that the NCCIH has undertaken this activity during a time when Federal agencies are implementing *Equity Action and Diversity Plans* pursuant to the Executive Order (EO) 13985, *Advancing Racial Equity and Support for Underserved Communities Through Federal Government*.⁷ One outcome of EO 13985 was the establishment of the White House *Interagency Working Group on Equitable Data*, which recently released recommendations on best practices for sharing information across the Federal

⁴ AAMC Comments to the *Congressional Social Determinants of Health Caucus* (September 20, 2021), <https://www.aamc.org/media/56566/download?attachment>.

⁵ AAMC Comments to the White House Office of Science and Technology Policy, *Request for Information on Strengthening Community Health Through Technology* (March 30, 2022), <https://www.aamc.org/media/60171/download>. In this response, the Center expresses concern for the disproportionate impact of algorithmic bias in machine learning.

⁶ *Data for Health Equity: the Foundation for Creating Healthier Communities* (2021), <https://www.youtube.com/watch?v=opRWK08DIsl>

⁷ AAMC Comments to the OMB on *Methods and Leading Practices for Advancing Equity and Support for Underserved Communities Through Government*, OMB 2021-0005 (July 2, 2021); <https://www.aamc.org/media/55326/download?attachment>. Also see, *Biden-Harris Administration Releases Agency Equity Action Plans to Advance Equity and Racial Justice Across the Federal Government* (April 14, 2022).

government while also addressing inequities.⁸ Further, a primary recommendation from the Working Group was the proposed revisions to the Office of Management and Budget’s (OMB) *Standards for Maintaining, Collecting, and Presenting Federal Data on Race and Ethnicity*.⁹ We strongly encourage NIH/NCCIH coordinate with the OMB and other agencies to develop a cohesive strategy that is conscious of the potential for increased bias and discrimination without a coordinated, iterative approach to developing a standardized framework.

As recommended throughout this letter, and evidenced by the Center’s crowdsourcing activity, community engagement should be the bedrock for any effort to develop a standardized determinants of health research strategy (i.e., NCCIH research strategy and “Common Data Elements Measurement Tool”) both at the individual and community level. It is also critical that it is one that can be easily accessed, utilized, and understood by all.

The AAMC Center for Health Justice is committed to advancing these efforts and would appreciate the opportunity to work with the NIH/NCCIH as it takes next steps to identify common determinants for whole person health. We would also be happy to provide additional information on the research and policy priorities of the Center, as well as potential opportunities for collaboration with our constituent community and health equity partners. For questions, please contact me (palberti@aamc.org) or my colleagues Daria Grayer (dgrayer@aamc.org), or Heather Pierce (hpierce@aamc.org).

Sincerely,



Philip M. Alberti, PhD
Founding Director, AAMC Center for Health Justice
Senior Director, Health Equity Research and Policy

cc: Helene M. Langevin, M.D., Director, NCCIH
cc: David J. Skorton, M.D., AAMC President and Chief Executive Officer

⁸ Equitable Data Working Group Report, *A Vision for Equitable Data Recommendations from the Equitable Data Working Group*, Page 5 (April 22, 2022).

⁹ “While OMB is actively working to help ensure the federal statistical system efficiently, effectively, and accurately captures the diversity of the American people, federal agencies, along with state and local partners, are also able to disaggregate data beyond OMB’s minimum classification categories for collection, tabulation, and reporting – as the U.S. Census Bureau did for the 2020 Census data collection. OMB is developing updated guidance to promote improved understanding of disaggregation already allowable under the current Statistical Policy Directive No. 15” *Id.*.