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Nakela L. Cook, MD, MPH Executive Director Patient-Centered Outcomes Research Institute (PCORI) 1828 L Street, NW, Suite 900 Washington, DC 20036

Via Electronic Submission (<u>https://www.pcori.org</u>)

## Re: PCORI's Proposed Research Agenda for Public Comment

Dear Dr. Cook:

The Association of American Medical Colleges (AAMC) appreciates the opportunity to submit comments to the Patient-Centered Outcomes Research Institute (PCORI) about the *Proposed Research Agenda*.

The AAMC is a nonprofit association dedicated to transforming health through medical education, health care, medical research, and community collaborations. Its members are all 155 accredited U.S. and 17 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 186,000 full-time faculty members, 94,000 medical students, 145,000 resident physicians, and 60,000 graduate students and postdoctoral researchers in the biomedical sciences.

The AAMC supports PCORI's strategic planning process, and we understand the importance of creating a research agenda to direct the Institute's future funding. Our statement<sup>1</sup> submitted in response to the proposed National Priorities for Health endorsed the five priority areas that PCORI identified as long-term goals to guide PCORI's Research Agenda. We encourage PCORI to review our statement, as it is also relevant to the concepts presented in the Proposed Research Agenda. Below, we've included other general comments.

Research Agenda Statement: Fund research that aims to achieve health equity and eliminate health and health care disparities

The AAMC fully endorses PCORI's emphasis on identifying research opportunities to advance health equity and eliminate health and health care inequities. The AAMC founded the <u>Center for</u> <u>Health Justice</u> in 2021, and its goal is for all communities to have an opportunity to thrive—a

<sup>&</sup>lt;sup>1</sup> See AAMC Comment Letter, <u>*PCORI's National Priorities for Health: Proposed Priorities for Public Comment*</u> (August 27, 2021).

goal that reaches well beyond medical care. Achieving health equity means addressing the common roots of health, social, and economic injustices and implementing policies and practices that are explicitly oriented toward equal opportunity. The 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. The AAMC is committed to addressing health inequities and we appreciate PCORI's focus on health equity as a core component of its research agenda.

Research Agenda Statement: Fund research that fills patient- and stakeholder-prioritized evidence gaps and is representative of diverse patient populations and settings Research benefits from engagement and co-creation with patients and other stakeholders throughout all stages of the research process—from developing the initial research questions, to identifying approaches for communicating research findings. Developing partnerships within communities they serve enables researchers to seek insight from key stakeholders about studies, questions, and outcomes of direct import to diverse populations. Above all, establishing effective community collaborations requires the essential element of trust, and we encourage PCORI and its grantees to access the AAMC Center for Health Justice's <u>Principles of Trustworthiness</u> toolkit as a resource. We also recommend that PCORI align the efforts of its proposed Science of Engagement Funding Initiative with the proposed research agenda. **Please see the additional feedback we provided in our response**<sup>2</sup> to **PCORI's Science of Engagement Funding Initiative request for information (RFI)**.

<u>Research Agenda Statement: Fund research that builds the evidence base for emerging</u> <u>interventions by leveraging the full range of data resources and partnerships</u> The AAMC supports funding studies that use data for research purposes and encourages PCORI to collaborate with federal agencies, community organizations, and other stakeholders in efforts to gain consensus around what is needed to improve and evaluate the accessibility of data for use in research. For example, how to harmonize common data models, enhance the health data infrastructure, and develop a standardized national sociodemographic data collection system to assist with documenting inequities. The AAMC Center for Health Justice held a hill briefing in July 2021, "Data for Health Equity: the Foundation for Creating Healthier Communities," which addressed the need for multisector data alignment across the entire health ecosystem to support partnerships and evaluation of effort.

Additionally, the AAMC supports PCORI's commitment to advancing open science, and as we noted in our response<sup>3</sup> to the proposed National Priorities for Health, "We urge PCORI to ensure

<sup>&</sup>lt;sup>2</sup> See AAMC Comment Letter, <u>*PCORI Request for Information: Science of Engagement Funding Initiative</u> (November 19, 2021).</u>* 

<sup>&</sup>lt;sup>3</sup> See AAMC Comment Letter, <u>PCORI's National Priorities for Health: Proposed Priorities for Public Comment</u> (August 27, 2021).

that the data sharing requirements for its grantees are aligned with those issued by other granting agencies and are supported through: funding mechanisms that recognize the costs of meaningful data sharing; clear and transparent criteria for evaluating the sufficiency of grantees' efforts; encouragement and identification of databases that follow the FAIR principles<sup>4</sup>; and the use of persistent identifiers to allow researcher to track the reuse of and receive credit for their data.<sup>5</sup>"

While it is important to build evidence for emerging interventions, this proposed research agenda statement does not reference studying existing interventions (whereas the corresponding Priority Area for Health references both). We recommend that PCORI continues to fund comparative clinical effective research (CER) studies that examine not just innovative approaches, but how patients respond to existing treatments where there remain questions about an intervention's utility and research could inform the need to change an existing practice.

<u>Research Agenda Statement: Fund research that focuses on health promotion and illness</u> <u>prevention by addressing health drivers that occur where people live, work, learn, and play</u> We appreciate PCORI's acknowledgement that factors impacting health extend beyond the traditional health care setting. The AAMC's Center for Health Justice is committed to this concept and is forming a <u>Multisector Partner Group</u> to help inform the Center's programming, research, and partnership activities. We support PCORI's intention to identify ways to expand research partnerships so that studies can benefit from experts representing a broad set of disciplines, including collaborations with community members and organizations.

<u>Research Agenda Statement: Fund research that integrates implementation science and that</u> <u>advances approaches for communicating evidence so the public can access, understand, and act</u> <u>on research findings</u>

We support PCORI's continued commitment to make research findings actionable through funding implementation and dissemination awards. These studies aid in the adoption of evidence into practice and PCORI's new Health Systems Implementation Initiative (HSII) will help to further increase the uptake of research findings in the clinical care settings. For research to have the greatest benefit to patients, emphasis should be given to how study results are communicated not only to research participants, but also to the general public and others in the broader health care community.

In summary, the AAMC appreciates the opportunity to submit these comments, as well as the feedback related to the National Priorities for Health, and the AAMC supports PCORI's Proposed Research Agenda and overall strategic planning process. If you have any questions

<sup>&</sup>lt;sup>4</sup> Wilkinson, M., Dumontier, M., Aalbersberg, I. *et al.* The FAIR Guiding Principles for scientific data management and stewardship. *Sci Data* **3**, 160018 (2016). <u>https://doi.org/10.1038/sdata.2016.18</u>.

<sup>&</sup>lt;sup>5</sup> Pierce, H., Dev, A, Statham, E., and Bierer, B. Credit data generators for data reuse. *Nature* **570**, 30-32 (2019) (<u>https://www.nature.com/articles/d41586-019-01715-4</u>.

regarding this response, please feel free to contact me or my colleagues, Anne Berry, Lead Specialist, Implementation Research and Policy (aberry@aamc.org), or Olufunmilayo Makinde, Health Equity Research Analyst (omakinde@aamc.org).

Sincerely,

Ross M. King (. M)

Ross McKinney, Jr., MD Chief Scientific Officer