



August 27, 2021

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

***Re: PCORI's National Priorities for Health: Proposed Priorities 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 National Priorities for Health*.

The AAMC is a not-for-profit 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; more than 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 their more than 179,000 full-time faculty members, 92,000 medical students, 140,000 resident physicians, and 60,000 graduate students and postdoctoral researchers in the biomedical sciences.

The AAMC supports PCORI's strategic planning process and the Institute's development of these priorities around long-term goals for health. We feel these priorities serve as effective pillars on which PCORI can build its research agenda, and we provide the following comments.

Increase Evidence for Existing Interventions and Emerging Innovations in Health

PCORI research generates meaningful evidence to better inform health care decision-making. We support PCORI's acknowledgment of the need to study both existing treatments and emerging innovations. However, for existing treatments, we encourage PCORI to focus particular attention on those interventions that have lingering questions about their utility, where there is a meaningful potential for the research to identify a need to change existing practices.

We also appreciate PCORI's recognition that innovations can potentially introduce undue burdens and increase disparities in health care, so emphasizing the importance of understanding and studying the benefits and risks for adopting new practices is critical. Additionally, as PCORI has identified, there is a need to ensure that these studies include populations from diverse backgrounds, specifically those who have been traditionally underrepresented in medical research.

### Enhance Infrastructure to Accelerate Patient-Centered Outcomes Research

PCORI created PCORnet, a national network that expedites the research process by providing researchers with access to large amounts of data and other forms of health information. The AAMC hopes that PCORI will continue to support and build upon the success of this interoperable data network that allows clinical effectiveness research to be conducted more efficiently. We recommend further collaboration with federal health agencies and key stakeholders to gain consensus for how to harmonize common data models and enhance health data infrastructure.

Additionally, the AAMC supports PCORI's commitment to advancing open science as evidenced by its *Policy for Data Management and Data Sharing* and we recommend that PCORI continue these efforts moving forward. We urge PCORI to ensure 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>1</sup>; and the use of persistent identifiers to allow researcher to track the reuse of and receive credit for their data.<sup>2</sup>

### Advance the Science of Dissemination, Implementation, and Health Communication

PCORI has exhibited its commitment to disseminating and implementing research findings in ways that consider stakeholder needs and provide strategies to facilitate the adoption of evidence into practice. PCORI's dissemination and implementation awards help to make research findings actionable. Emphasizing the importance of this concept in PCORI's future research agenda will help bridge the gap between evidence generation and uptake. We also think that PCORI's new Health Systems Implementation Initiative (HSII), within PCORI's Dissemination & Implementation (D&I) program, will help to further advance efforts of building learning health systems and increasing uptake of research findings in the clinical care settings.

### Achieve Health Equity

The AAMC supports PCORI's approach that ensures PCORI-funded research takes into account systematic, avoidable, and unjust differences in health between patient populations, and emphasizes the inclusion and deep engagement of participants from groups that have been and continue to be marginalized in research and medical care. We encourage PCORI to ensure that patients, families, and communities are engaged as codevelopers across all aspects of the research process: from generating research questions, to crafting analytic plans, to reporting results, and adopting evidence-based strategies into practice. To facilitate this engagement requires that our research and medical care organizations demonstrate they are worthy of trust. AAMC encourages PCORI and its grantees to explore and utilize the [AAMC Center for Health Justice's Principles of Trustworthiness toolkit](#) to build that necessary foundation.

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<sup>1</sup> Wilkinson, M., Dumontier, M., Aalbersberg, I. *et al.* The FAIR Guiding Principles for scientific data management and stewardship. *Sci Data* **3**, 160018 (2016). <https://doi.org/10.1038/sdata.2016.18>.

<sup>2</sup> Pierce, H., Dev, A, Statham, E., and Bierer, B. Credit data generators for data reuse. *Nature* **570**, 30-32 (2019) (<https://www.nature.com/articles/d41586-019-01715-4>).

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Given the understanding that population and community health inequities are largely driven by factors beyond the purview of medical care, the AAMC strongly urges PCORI to reconsider its focus on “health equity” and instead set its sights on achieving “health care equity.” Considering health care equity, specifically, in all future research activities is of critical importance to ensure that the medical care and biomedical research systems focus their efforts on aspects of health that are almost exclusively under their control: equitable access to medical care services and equitable quality of medical care processes and outcomes. These should be the targets of PCORI-funded, health care equity-focused science.

The AAMC also recommends that PCORI work with federal agencies and other stakeholders to develop a standardized, national, sociodemographic data collection system to assist with not only the documentation of inequities but also, and more importantly, the identification of potential policy- and practice-based solutions to those inequities. To that end, and as outlined during AAMC Center for Health Justice’s [recent Hill briefing](#), “Data for Health Equity: the Foundation for Creating Healthier Communities,” we encourage PCORI to partner with organizations representing the broad health ecosystem—medicine and public health, of course, and also housing, transportation, education, etc.—to develop a common set of data elements that all sectors can use to develop and align the partnerships and collaborations needed to achieve health care equity inside our hospitals’ walls and health equity beyond them.

#### Accelerate Progress toward an Integrated Learning Health System

The AAMC agrees that moving toward an integrated learning health system will improve health outcomes for populations. We recommend that PCORI consider mechanisms for funding research that requires collaborative work across health systems in order to gain insight into methods and strategies for successful coordination. Additionally, we value PCORI’s commitment to providing training, educational support, and research opportunities (in collaboration with the Agency for Healthcare Research and Quality) to patient-centered outcomes researchers working within learning health systems. We support enhancing these funding opportunities and hope to see PCORI identify additional ways to support researchers and trainees in academic health settings.

In summary, the AAMC appreciates the opportunity to submit these comments and the AAMC supports the five priorities identified to inform PCORI’s research agenda. We recommend that PCORI identify areas of collaboration and coordination with federal health agencies as it continues to build upon these strategies. Additionally, we look forward to engaging further with PCORI as stakeholder input is sought throughout the strategic planning process. If you have any questions regarding this response, please feel free to contact me or Anne Berry, MPP, Lead Specialist, Implementation Research and Policy at [aberry@aamc.org](mailto:aberry@aamc.org).

Sincerely,

A handwritten signature in blue ink, appearing to read "Ross McKinney, Jr., MD". The signature is stylized and includes a small circular mark at the end.

Ross McKinney, Jr., MD  
Chief Scientific Officer