



November 16, 2021

Nakela L. Cook, M.D., M.P.H.
Patient-Centered Outcomes Research Institute
1828 L Street NW, Suite 900
Washington, DC 20036

Re: Response to RFI on Science of Engagement Funding Initiative

Dear Dr. Cook:

AcademyHealth welcomes the opportunity to provide input to the Patient-Centered Outcomes Research Institute (PCORI) on the potential development of a Science of Engagement funding initiative. We are the professional home of more than 3,000 health services researchers, policy experts, and practitioners, and we strongly support the production, dissemination, and use of evidence to inform policy and practice. Our membership is highly engaged with PCORI and its work, from informing the creation of the Institute to serving in PCORI's leadership to receiving funding support. AcademyHealth recognizes and applauds PCORI's unique contributions to the development and promulgation of practice- and policy-supporting evidence.

Given the growing awareness of and appreciation for meaningful engagement in health research, the announcement of PCORI's decision to develop a funding initiative around the Science of Engagement is very well received. Successful embrace of engagement, and ongoing advancement of the field, will require further development of related metrics, methods, and evidence.

While we generally celebrate PCORI's commitment to this work, and selection of priority areas in the [table on page 7](#) of the RFI, AcademyHealth believes that a strong foundation for high quality, high impact engagement is predicated on a truly patient-centered orientation. While AcademyHealth generally supports the topics outlined in the table, we urge PCORI to consider the unique implications of health research on patient/caregiver stakeholders – and to ensure there is no loss of focus or prioritization of these perspectives, relative to other stakeholders. To this end, PCORI should fund work specifically focused on these priority perspectives and their nuances.

That said, we acknowledge that many individuals identify with different and intersecting stakeholder groups. To acknowledge the ways various dimensions of diversity can factor into lived and disease experience, call for more explicit attention on exploring “what works for whom” and in what contexts. Reinforcing this, it will be crucial for principles of informed diversity, equity, and inclusion (DEI) to serve as both the foundation and through-line for this work. This should be clearly articulated in requests for proposals and explicitly evaluated as part of merit review.

Finally, recognizing PCORI's leadership role in promoting and advancing patient-centered outcomes research (PCOR), we hope that this work will serve as a continuation and furthering of existing work that has already been done in this and other related fields. There are valuable and [rapidly proliferating insights](#) emerging from our field, as well as from the related fields of team science, action research, community-based participatory research (CBPR), and others. We believe a strategic way forward for the field will *involve integrating and synthesizing existing learnings, while adapting this knowledge to inform innovations in PCOR and comparative effectiveness research (CER)*.



Research Priorities for Science of Engagement

As PCORI moves forward with supporting research in this area, it will be important to prioritize definitions and metrics, so they can provide the foundation for experimental and evaluative research that facilitates comparison and meta-analysis. In considering specific constructs, metrics should speak to engagement quality, assessing experience as well as engagement outcomes, and be developed to enable both formative (quality improvement) and summative (evaluation) assessments. The field needs measures that can inform teams how they are doing so they can learn and pivot in real time and maximize positive impacts from their engagement efforts. With respect to outcomes, the field needs to understand engagement's effects on the research process (e.g. how does it change how the work is done?), quality (e.g. more representative recruitment, better retention, assessment of outcomes important to patients, more complete data, shorter recruitment periods, etc.), and research impact and outcomes (e.g. dissemination and uptake, outcomes improvement). Outcomes should be both objective and perceived, and informed by both the patients/caregivers and researcher perspectives (e.g., perceived impact on research process).

An additional priority area for PCORI to pursue would be assessing the impact of engagement framed by an understanding of context. The field needs evidence that demonstrates the relationship between engagement and research quality/outcomes as well as the role of context in this relationship. Our field needs to look not only at intervention and outcomes, but the context in which those take place to help us understand the “why” behind the result. Impact evaluations of engagement in the form of experimental and quasi-experimental designs will be important, and they certainly build on the foundations of PCOR and CER already funded by PCORI, merely adapting them to new research topics. But factoring in the role of context will be important. We must ensure we move beyond ‘what works’ to ‘what works and why’. Absent this framework, we will not know why something worked in one place and not another, when the reality is, for example, staffing capacity was insufficient in one place but ample in another, or if historical abuses of a minority population generated mistrust that prevented an intervention from being implemented. Research is conducted in complex, multi-faceted and dynamic environments, which could mean that the same engagement approach would not work the same way in different contexts. Moreover, contextual factors that might constitute barriers in one setting may facilitate in others. Understanding how this happens will help the field address key challenges related to broader uptake of engagement practices as well as the normalization and sustainability of these practices once adopted.

We encourage PCORI to fund mixed methods studies that incorporate implementation science frameworks, particularly determinant frameworks, such as Consolidated Framework for Implementation Research (CFIR), Promoting Action on Research Implementation in Health Services (PARiHS), and Theoretical Domains Framework (TDF), as means to understand and explain what influences engagement practice outcomes, particularly with reference to priority subpopulations. The use of established frameworks that recognize that practice implementation is a multidimensional phenomenon, with multiple interacting influences would be invaluable in facilitating comparisons and learning across heterogeneous engagement strategies and research projects.

For example, community-based participatory research (CBPR) is an established framework for conducting community-engaged and policy-relevant research, and PCORI has provided significant support for CBPR research for several years on topics related to health disparities. More recently, the social determinants of health (e.g., food, housing, and income insecurity) have been more widely accepted and measures of social risks are being developed and refined as predictors of health outcomes. However, challenges remain when research teams who are not culturally informed and who are unfamiliar with successful community engagement strategies attempt to use approaches that don't recognize and respect the values, health behaviors, and health risks of those community members.

Intersectional frameworks, in which individuals are viewed as being affected by several sources of discrimination and risk at the same time (e.g., unhoused low-income Black female with Type 1 diabetes) consider the complexity of combined risks these individuals face in their communities. As a funder, *PCORI could do more to recognize the importance of diversity, equity, and inclusion (DEI) in the research projects it supports* by ensuring that community members with lived experience and social risks are engaged in meaningful leadership roles on research teams, beginning from the planning stages and continuing throughout the execution and dissemination stages.

Diversity, equity, and inclusion is a core value of our organization, and we have prioritized providing tools, resources, and support for researchers from marginalized and minoritized communities. In August, we [released](#) a report written by an Advisory Group on Diversity, Equity and Inclusion in Health Services and Policy Research (DEI in HSR), which sought to create a sustainable, action-oriented strategy for AcademyHealth to address DEI issues in HSR. Additionally, in recent months we have provided federal policymakers with blueprints for better engaging DEI issues. First, we [answered](#) the call of the National Institutes of Health (NIH) on how to advance and strengthen DEI in the biomedical workforce. Second, we [highlighted](#) the role that nurses can play as advocates against structural racism if they are given the training and tools to do so when the National Institute of Nursing Research (NINR) asked for comments on its new strategic plan. Third, we [provided](#) the Office of Management and Budget (OMB) with guidance on the methods, tools, and leading practices for advancing equity and support for underserved communities.

AcademyHealth's [Paradigm Project](#), a multi-year initiative to develop, test, and spread bold innovations to enhance the relevance of health services research for policy and practice, has underscored the need for our field and health care broadly to address structural racism in all its institutions. Our use of human-centered design in the Paradigm Project has *demonstrated that achieving DEI requires innovations in how the field undertakes scientific inquiry, and changing the way we do science to achieve greater impact cannot happen without DEI*. For example, one innovation we are developing to help health systems to access and apply published research in the care they provide has also evolved through stakeholder input to become a tool for addressing disparities in care and empowering community-based organizations as agents of change.

Considerations Related to Bias

In exploring the study within a study (SWAS) model, *we urge careful consideration to how PCORI will assess and mitigate the potential for bias*. Specifically, groups engage in a way that they assume will be successful, thus creating a project (outcomes, investigators, methods, etc.) that will reinforce that success. We encourage PCORI to consider the value of ensuring third parties are embedded to conduct the SWAS, in much the same way an effective and unbiased evaluation would be structured.

In both SWAS and standalone studies, we advocate the involvement, if not the leadership, of non-scientific stakeholders (patients, patient advocacy groups, skilled engagement professionals) in the actual evaluation or study to reduce the risk of academizing the study. *We also advocate for representation of people who reflect diverse racial, ethnic, and gender identities to help mitigate bias where it exists along the research enterprise continuum*. While it is important to measure success, it is just as important to consider who is defining success, and whom that definition privileges. Evaluation outcomes should [reflect](#) inclusively defined, equitable measures of success.

Thank you for the opportunity to discuss the science of engagement funding proposal. For further comment, clarification, or inquiry, please email Josh Caplan at Josh.Caplan@AcademyHealth.org.