



April 19, 2022

Robert Otto Valdez, Ph.D, M.H.S.A.
Agency for Healthcare Research and Quality
5600 Fishers Lane
Rockville, MD 20857

Dear Dr. Valdez:

AcademyHealth welcomes the opportunity to provide input to the Agency for Healthcare Research and Quality (AHRQ) on its proposed strategic framework for AHRQ's Patient-Centered Outcomes Research Trust Fund (PCORTF) investments. We are the professional home of 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 AHRQ, and we recognize and support AHRQ's mission to make healthcare safer, while also improving quality, equity, and affordability. We appreciate that AHRQ has asked for comments from the community about how to use the PCORTF in a manner that best improves the quality, safety, equity, and value of healthcare delivery for patients.

General Comments on the Mission, Overarching Vision, and High-Level Goal

We recommend that the mission statement of the framework include a stronger statement of representativeness of communities and populations across the health system. It is critical and within the existing mission of PCOR and AHRQ to train not only researchers, but also provide stakeholders with the education and resources for dissemination and implementation.

Our suggested edit: *Synthesize and support the dissemination and implementation of evidence into practice and train the next generation of patient-centered outcomes researchers **and stakeholders to implement patient-centered outcomes research effectively and equitably.***

With this edit, we believe that the mission, overarching vision, and high-level goals are sensible, although we do have concerns about ensuring how these outcomes are met, as discussed below. Achieving desired outcomes requires the empowerment and coordination of multi-disciplined and multi-leveled stakeholders connecting, interacting, and working meaningfully together. AHRQ should ensure that collaborative efforts are not hindered by unequal and discriminatory power structures, or a failure to ensure that diverse voices, experiences, and actors are engaged in the development and implementation of the PCORTF strategies. Individuals and communities of color and/or low-income that are most negatively affected by health disparities should be engaged in a thoughtful, intentional, deliberate, and meaningful manner in research design, dissemination, and evaluation activities.

Inclusionary practices are key for AHRQ to have the greatest success at achieving this mission. Inclusion is not a passive act; it requires constant and proactive actions. For example, AHRQ could create a diversity, equity, and inclusion (DEI) committee of AHRQ staffers that meet regularly to evaluate the progress in inclusion with AHRQ grant programs. These evaluations should be both retrospective of grants already administered and proactive before awards are released. In addition, transparency and accountability for progress on health equity at the Agency could be established through a sub-committee of the AHRQ National Advisory Council and regular public reports.



To help sustain progress towards the high-level goals, AHRQ should also invest in broader training and shared learning on progress toward fully developed learning health systems (LHS), specifically in advancing studies of effectiveness where the findings are understandable, relatable, appropriate, and replicable.

High Level Priorities and Desired Outcomes

Health Equity

Achieving health equity and identifying and eliminating health disparities is a key priority for AcademyHealth, AHRQ, and PCORI. It is good that health equity is a specific and first principle in the framework, but it also must be included as a feature in each of the other pillars. Health equity is not a silo—it is a concept that should run horizontally through all of AHRQ and PCORI’s work. To achieve an equitable health care system, first the US must acknowledge the structural biases inherent in the system. Health systems need to work to be anti-racist and anti-classist organizations and there needs to be more than collaboration with communities. There needs to be representation of communities within the care team and the health system leadership, and there needs to be a proactive effort to break down silos that have created structural biases in systems and medical education. Structural racism and inequities are not a coincidence of declining trust in the healthcare system or in distorted care patients with chronic conditions experience, but rather some of the driving forces.

Tokenistic, “check the box” engagement is insufficient. Engagement with underrepresented communities in training and implementation initiatives must be meaningful with the communities as equal partners and with a focus on investing in collaboration, capacity, and capabilities. Research funding opportunities should require that investigators meaningfully engage and incorporate members of under-resourced communities as partners in conducting the research determining research priorities and questions, study design, implementation, analysis, reporting, and translation into practice and policy. A key component here is “meaningfully”. This means that applications for funding should be required to describe how these communities were engaged in the process of priority-setting to develop the research questions and the study design proposed, as well as how researchers will continue to involve community members throughout the research cycle. It also means researchers from underrepresented backgrounds must be proactively notified of opportunities for funding. As part of the application review and funding decisions, explicit criteria and weight should be given to these aspects so that investigators are rewarded for their innovation and attention to these dimensions. Patients, families, and caregivers should be partners in the design processes, trainings, and implementation. Co-designing research projects with the individuals most impacted by the research, including people with lived experience and expertise, as well as subject matter experts across the lifespan (especially with dependent populations, i.e. children, individuals with disabilities, and the elderly), will enhance uptake, impact, and sustainability.

Additionally, AHRQ can lead with targeted investments in developing and disseminating best practices for collecting and using race, ethnicity, language, sexual orientation, and gender identity data to better measure and improve health equity along several dimensions.

Suggestions:

- Proactive anti-racism should be explicitly included in the framework.
- PCORITF funding opportunities must include resources to ensure researchers from underrepresented backgrounds have plenty of notice and opportunity to apply.
- Co-design research projects with the communities and individuals impacted, with a focus on meaningful and prolonged engagement.

- Critically embrace the role of health inequities and disparities within each of the priorities.
- Require that research plans have engagement and DEI milestones and metrics and be held to them during project execution.

Patient, Family, and Provider Experience of Care that Enhances Trust in the Healthcare System

Current measures of trust in the healthcare system are insufficient. More investment is needed to determine how to operationalize trust and trustworthiness, develop and test new trust-building practices, and disseminate these broadly to health systems and health professional organizations. This should include research on helping clinicians trust their patients and balance the unequal power dynamics between the clinician and patient when it comes to their care. Whole-person care requires providers and researchers to listen to patients and communities without judgment. For people who have experienced generational trauma due to structural racism, researchers and providers must have the resources and opportunity to implement trauma-informed principles in their clinical discussions, and ensure their research hypotheses account for such trauma.

There is too little work currently being undertaken on the trust that clinicians and providers have in their organization or the health system. Research on which health system practices and policies will build – or re-build – trust by clinicians in the organizations is needed across a variety of settings and contexts as history and other factors are salient in these relationships. More investments should be made in understanding the impact of organizational representativeness and trust on clinician retention, well-being, and patient outcomes.

As noted above, issues of health equity and disparities need to be included at every priority. Health disparities and structural racism are a factor in the loss of trust in the healthcare system among underserved populations. Building and enhancing trust must occur alongside meaningful collaboration when identifying social determinants of health (SDOH), such as affordable and safe housing, accessible transportation, internet access, nutritious food, social isolation, etc.

Improving Dissemination and Implementation of Patient-Centered Outcomes Research (PCOR) Evidence

The COVID-19 pandemic has shown that there is a disconnect between primary care, public health, and local, state, and federal government officials. AHRQ should continue investigating new innovations and opportunities for collaboration and communication, test them, and disseminate and support them.

One important strategy in achieving this goal is to enhance and expand statewide capacity to achieve primary care transformation through partnerships between health system leaders and state policymakers, including Medicaid programs. The pandemic underscored how critical state policy is in facilitating, or hindering, not only system capacity (e.g. through telehealth and licensing rules) and AHRQ has an opportunity to build on the lessons learned over the last two years to further strengthen primary care, health equity, and health system capacity and resilience.

A second important strategy to implementation of PCOR evidence is through further expansion and support of patient ambassadors (e.g. [PCORI Ambassadors](#)) as they can be unique and effective connectors between AHRQ and the health care system. This volunteer network of individuals could be called in to assist in, designing, sharing, operationalizing, and scaling comparative effectiveness and patient-centered outcomes research and principles. AHRQ can invest in supporting and expanding the Ambassador network with the goal of educating policymakers and entities about the PCOR breakthroughs that are being funded.

A third strategy that AHRQ should further develop is its role in digital health. Effective ways to ensure sustainability of initiatives that enhance the integration of PCOR findings into practice include the development of FAIR (Findable, Accessible, Interoperable, and Reusable) data LHS process that provides replicable PCOR and knowledge artifacts with the goal of serving diverse healthcare delivery systems. Currently in the LHS, there are too many siloed processes and too little communication across facilities and institutions.

Aspects of the Framework that do not address major challenges faced by the US healthcare system

“Cost” is mentioned only one time in the cross-cutting strategies for achieving desired outcomes, and it is unclear if this is intended to represent costs to the health system, the patient, or both. Historically, researchers have experienced barriers in undertaking and disseminating patient-centered research that includes costs. Specifically, there have been concerns that patient-centered research should be limited to the clinical practice of medicine, which ignores the many factors that affects patients’ and clinicians’ ability to deliver the best possible care at the best value and equitably to a range of patient populations. Patients, caregivers, and providers need to understand the cost implications of treatment choices that are being made. Financial and other hardship considerations are real and demonstrated issues in patient health care decisions, and incorporating and disseminating information to inform these decisions better aligns research with real-world experiences. Indeed, some have described financial harm due to medical care as another dimension of patient safety.

More than one in four Americans [reports](#) difficulty paying their medical bills, and increased costs to patients have been shown to negatively affect their ability to follow their care plan, reduce access to care and increase mortality. Even patients who may not have high out of pocket direct medical costs report concerns about transportation, lost income, extended time spent at visits, childcare issues and the myriad of related indirect costs of care. Communities of color and low-income populations [face](#) the heaviest of these burdens.

Given the continued growth in health care spending as a percent of GDP, the reasons for investing in cost research goes beyond its direct implications for patients and families. Due to its importance for employers and other purchasers, public and private payers, and society at large, the framework should explicitly emphasize the need to understand and compare the benefit of medical interventions relative their costs.

The 2019 reauthorization of PCORI (Pub. L. 116–94, div. N, title I, § 104(a)) emphasized both the importance and statutory mandate for cost-related analysis for either patients or system wide: *“In addition to the relative health outcomes and clinical effectiveness, clinical and patient-centered outcomes shall include the potential burdens and economic impacts of the utilization of medical treatments, items, and services on different stakeholders and decision-makers respectively. These potential burdens and economic impacts include medical out-of-pocket costs, including health plan benefit and formulary design, nonmedical costs to the patient and family, including caregiving, effects on future costs of care, workplace productivity and absenteeism, and healthcare utilization.”*

Furthermore, with the advent of CMS price transparency requirements, new data on prices actually paid (not billed charges) will be coming online rapidly. The importance of and correlations between cost and high-value care should be made clear in this Framework, and the research it drives. For reference, see our recent [communication](#) with PCORI on their Proposed Principles for the Consideration of the Full Range of Outcomes Data.

Using PCORTF resources to test new ways of soliciting, selecting, and funding research and other activities to achieve goals.

We know that our current process for soliciting, reviewing, and selecting grants and contracts in the existing federal process has been inadequate in reaching certain goals – namely more impact, a more diverse grantee pool, and more timely, accountable progress on key aims. As is said – “every system is perfectly designed to achieve the results it gets”!

We encourage AHRQ to use an approach of experimentation and innovation in how it executes on its PCORTF spending plan. The existing grant review process could be modified and evaluated to assess the impact of changes as other funding agencies around the world are doing. In addition, AHRQ should consider using additional levers (e.g. accountability, showcasing and elevating diverse voices, etc.) at its disposal to support its partners and move its funded research community toward its ultimate goal of equitable, whole person care across the lifespan.

Measuring progress and impact of PCORTF investments

AHRQ should be directly engaged with, and regularly polling, relevant stakeholders, communities, and PCORI Ambassadors on basic questions of impact and success. For example, asking:

- What do you see that is missing in PCORTF’s portfolio relative to measuring impact?
- What research methods are currently being developed to best capture true measurable impact that should be implemented? What methods are problematic or unreliable for under-resourced communities?
- How can we strengthen and accelerate dissemination and implementation of PCOR?
- How can we ensure that dissemination and implementation impacts communities equitably and centers communities that are historically marginalized by these efforts?
- What aspects of your community are equity measures missing or are not relatable/relevant?

To conclude, we appreciate the work that has gone into developing the PCORTF investment strategy. We believe that it is a sensible strategy, but one that could be strengthened with additional and explicit focuses on underserved communities and proactive, multi-pathway dissemination and implementation of PCOR.

For further comment, clarification, or inquiry, please email Josh Caplan at Josh.Caplan@AcademyHealth.org.