May 19, 2022

Robert Otto Valdez, PhD, MHSA
Director
Agency for Healthcare Research and Quality
5600 Fishers Lane
Rockville MD 20857

RE: Request for Information: AHRQ's Proposed Patient-Centered Outcomes Research Trust Fund Strategic Framework, issued February 18, 2022

Comments submitted to: PCORTF@ahrq.hhs.gov

Dear Director Valdez:

The American Medical Informatics Association (AMIA) appreciates the opportunity to respond to the RFI on the Agency for Healthcare Research and Quality's proposed Patient-Centered Outcomes Research Trust Fund strategic framework. AMIA is the professional home for more than 5,500 informatics professionals, representing frontline clinicians, researchers, and public health experts who bring meaning to data, manage information, and generate new knowledge across the health and healthcare enterprise. As the voice of the nation's biomedical and health informatics professionals, AMIA plays a leading role in advancing health and wellness by moving basic research findings from bench to bedside, and evaluating interventions, innovations and public policy across settings and patient populations.

We commend AHRQ for its efforts to further evolve a strategic framework to guide patient-centered outcomes research investments for the future. The AMIA Public Policy Committee designated seven key pillars as core to health informatics policy. Two of these pillars - Patient Empowerment and Population & Public Health, are directly relevant to this RFI and inform AMIA's response. This response was developed by four AMIA member experts and its content was reviewed by the AMIA President and Board Chair.

Patient Empowerment

AMIA believes:

1. Policies, programs, research, and care delivery should seek to empower patients through access to and control of their personal health information.
2. Health informatics is key to enabling delivery of patient-centered care.
3. Patients have a vital role to play in the development of public policy as well as publicly-funded programs & research.

Relevant to this RFI, AMIA supports:

*Ongoing and enhanced efforts to fund research that contributes to and advances the design and evaluation of digital technologies that enable patients to manage their own health and that of their families.

*Patients' efforts to design, test, and validate new technologies that help them manage their health and the health of their families.

We encourage AHRQ to recognize the role of health informatics as a key component of its patient-centered outcomes research (PCOR) strategic framework, as well as workforce development (including consumer health informatics) for growing data science capacity for PCOR. We also encourage AHRQ to incorporate a patient-centered component in all RFI provisions and to include the use of stronger language to indicate that all activities addressed in the framework must be approached with an equity first lens.

Population & Public Health

AMIA believes:

1. Everyone should have equitable opportunities to live a healthy/healthier life, regardless of who they are, where they live, or socioeconomic circumstances.
2. When medical, social services, and public health entities work together, everyone benefits.
3. All U.S. health system stakeholders should be accountable to their communities to assure conditions for a healthy life.
4. A balance between healthcare and public health investments should consider the value of preventive community-based services to support individuals to live healthy lives.
5. A systems- and standards-based approach for addressing social determinants of health and other factors that influence health should be integrated into health system workflows to support improved health outcomes.

AMIA supports:

*Better (1) integration, (2) interoperability, and (3) bi-directional sharing of data (including read and write back API capabilities), information, and knowledge across care delivery, public health agencies, and community-based organizations to inform policy, drive prevention and disease management efforts, and support community resource information sharing.

*Work to develop nationally scalable, multi-jurisdictional approaches to common public health workflows (e.g., electronic case reporting) for broad dissemination.

*A research agenda focused on (1) developing real-time public health-primary care information loops; (2) improving strategies to engage individuals to assess and promote health (e.g., mobile or virtual technologies); and (3) developing tools to assess social determinants of, and other factors that influence health.
*Development of more sophisticated approaches for protecting an individual's confidentiality while implementing strategies to improve population health outcomes.
*Investment in public health informatics workforce training to build competencies and capacities at every level where information is generated, managed, and used for population health.

Again, AMIA encourages AHRQ to recognize the role of informatics in the strategic framework.

In the table below, we have included text from the RFI in the left column, with AMIA's comments on select provisions corresponding on the right. Thank you for your consideration of these comments.

Sincerely,

Gretchen Purcell Jackson, MD, PhD, FACS, FACMI, FAMIA
President and Board Chair, American Medical Informatics Association

AHRQ's Proposed Patient-Centered Outcomes Research Trust Fund Strategic Framework

AHRQ's PCORTF Strategic Framework	AMIA's Response
Mission: Synthesize and support the dissemination of evidence into practice and train the next generation of patient-centered outcomes researchers	
Overarching Vision: Equitable whole-person care across the lifespan	
High Level Goal: Improve health outcomes by promoting high-value, safe, evidenced-based, integrated, coordinated, team-based, patient-centered care, with a focus on underserved populations.	AMIA suggests that AHRQ consider adding "equitable" to the high-level goal.
High Level Priorities and Desired Outcomes	
Desired Outcome A:	

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Health Equity	
1. Reduce health disparities for AHRQ's priority populations	
2. Engagement of underrepresented communities in training and engagement initiatives	Patients do better with providers "who look like them." There is a demonstrated need to train more providers, especially physicians and nurses from underserved communities. Engagement of communities must be a national initiative, not focused on just a few select areas or target populations.
3. Improved equity in access to needed care	
Desired Outcome B: **Prevention and improved care of patients with chronic conditions**	The goal of improved care for patients with chronic conditions is laudable given the number of patients with complex and comorbid conditions. However, early intervention must be a strong focus for all populations.
1. Increased uptake of evidence-based preventive services, early intervention and secondary prevention.	Research alone does not translate into healthcare for the underserved. Translational research must be a focus, with an overarching goal of reducing barriers to research in smaller communities. Increased partnerships between large medical centers and smaller community care settings should be explored. There must also be a stated recognition of cultural aspects of care among diverse populations. Additionally, it is necessary to address and forestall to the extent possible inequities brought about by artificial intelligence applications.
2. Decreased fragmentation of care for patients with multiple chronic conditions	
3. Co-design of innovations of care with patients and communities	
Desired Outcome C: **Patient, family, and provider experience of care that enhances trust in the healthcare system**	Improving the health care experience is challenging while serving patients who face homelessness and other determinants of health. Prioritization should be given to initiatives that work across disciplines to reach and assist the most vulnerable populations. This presents an

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	opportunity for focus on interoperability to improve communications regarding patient care. There must also be recognition that information blocking continues to be a barrier.
1. Improve patient/family engagement and reported experience of care	Leveraging community feedback is essential to improve patient/family engagement and reported experience of care. This outcome ties to the concepts of user-centered design and community engagement in research models.
2. Focus on whole-person care, with attention to mental health and social determinants of health	AMIA strongly supports this provision. There should be a focus on innovative ways to provide access to mental health care. Post pandemic, mental health care will be a critical part of addressing whole person care. Over reliance on artificial intelligence driven applications is unlikely to prove sufficient. Outcome based studies are needed to study new innovations to prove efficacy. Efforts are needed to ensure that the development and promotion of these tools does not leave a portion of the population behind.
3. Improved provider wellness and prevention	Provider wellness is an integral component of ensuring access to care and the delivery of optimal patient care. This concept was important prior to the pandemic and is even more so now. Organized medicine has demonstrated through peer reviewed studies the causes of provider burnout, including documentation burden, workflow inefficiencies, and the work environment. A greater focus is needed on assessing physician stress and finding ways to address it.
Desired Outcome D: **High-quality, safe care that is aligned with national health priorities**	
1. Transformation of healthcare organizations into learning health systems	The overarching concept of transformation of healthcare organizations into learning health systems is an important step forward. This transformation must apply to health care provided in all settings. For clarity, does AHRQ envision this as a pluralistic or whole of nation approach to building capacity that follows the vision of equitable, person-centered care across the lifespan?
2. Increased uptake of evidence-based practices that strengthen healthcare quality, safety and value	Does AHRQ consider evidence only from research, or is there an opportunity to incorporate evidence from practice? There is a need for real world data to be translated into evidence that can in turn be applied in learning health systems. This concept requires significant infrastructure funding and support.

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3. Improved outcomes for targeted national priority conditions	Maternal health must be a focus for this nation.
Desired Outcome E: **Primary care transformation**	
1. Uptake of new models of primary care, leveraging digital healthcare 2. Integrated, team-based behavioral health 3. Identification and provision of needed resources for comprehensive primary care and uptake of evidence	
Cross-Cutting Strategies for Achieving Desired Outcomes	
1. Train and support the next generation of health service researchers with a focus on team science and advancing health equity	The concept of training and support of the next generation of health service researchers should be strengthened to not only focus on team science and advancing health equity, but to emphasize the need to train researchers to have an equity first lens. This could be defined as an outcome or as part of each cross-cutting strategy. PCORTF is encouraged to create shared resource models to address health services researcher training innovation. An example would be the implementation of collaborative partnerships between institutions traditionally resourced and funded, and programs with lesser resources and grant opportunities. In addition, the concept of training researchers should be broadened to include research designed "with" patients and family and not "for" patients.
2. Develop and maintain the AHRQ infrastructure needed to synthesize and accelerate evidence into practice.	As stated above, AMIA believes this core infrastructure is an integral component of the strategic framework.
3. Leverage and support innovation in digital health, clinical decision support, and new models of care.	The concepts of innovation in digital health, clinical decision support, and new models of care should incorporate a patient-first and caregiver focus. These concepts should not be focused on providers. Clinical decision support should serve as the bridge between patients and providers to enable a dialogue to explore treatment options. AHRQ should consider adding the concept of

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	shared decision-making to this cross-cutting strategy. The focus on new delivery models should not be on providers, but on patients taking an equal part in maintenance of health. AHRQ should invest in programs that elevate patients' health literacy and optimize patient facing health information sources. These domains represent a key element of the knowledge base required for patient oriented shared decision making that contributes to high value, safe outcomes.
4. Build data, measurement, and analytic capacity to benchmark and evaluate uptake and use of evidence in learning health systems to improve outcomes that matter to patients.	
5. Accelerate the uptake of evidence in practice to optimize individual and population health and achieve health equity for all	
6. Disseminate evidence to Federal/State/Local healthcare decision makers with targeted communications strategies.	
7. Provide the evidence to inform policy changes needed for sustainable implementation and incorporation of evidence by healthcare systems, practices and providers.	AHRQ should emphasize the concept of patient-centered care when providing evidence to inform policy changes. Additionally, AHRQ should ensure that evidence is reproducible to enhance the level of trust among patients, policymakers, and other stakeholders
8. Evaluate the impact of PCORTF investments on care delivery, quality, costs, health outcomes, and health disparities.	AHRQ should evaluate "affordability" in addition to care delivery, quality, costs, health outcomes and health disparities.
AHRQ RFI Broad Questions	**AMIA's Response**
1. AHRQ would like overall reactions to the strategic framework; is there any aspect of the framework that: a. Does not promote the vision of advancing equitable whole-person care across the lifespan?	There appears to be an implicit assumption that "better" research will translate to better outcomes for all patients, especially underserved and underrepresented communities. This is not likely to occur. Targeted research and implementation science with stated explicit goals is needed to advance equitable, whole-person care. In addition to the stated goals, PCORTF could help foster the dissemination of best practice examples to translate research findings to actual improvement in outcomes.

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b. Does not address major challenges faced by the U.S. healthcare system?	Affordability of healthcare remains a major obstacle to care. This critical factor is not addressed in this framework. If the best care is unaffordable, it may as well not exist to those who can't afford it. For example, if patients do not have devices or internet access, access to care is limited in settings of virtual care. As innovations in care are developed, a key factor to keep in mind is that equipment must be accessible to diverse populations.
c. Could be improved (and if so, how)?	Efforts should be made to address communication of the strategic plan mission, vision, goals, priorities and outcomes, in a way that does not polarize policymakers and stakeholder communities.
2. AHRQ would like input on our (non-ranked) high-level priority areas: a. Do our proposed high-level priorities miss any areas of critical importance?	As noted above, AHRQ should focus on maternal care in all populations. AHRQ should add a focus on LGBTQ+ research and equity. For example - when do lab result parameters reflect the gender at birth and when do they reflect the new gender due to transformation? Again, this concept reflects the need to train researchers with an equity first lens.
b. Are any of the high-level priorities more important than others?	AMIA does not believe any of these high-level priorities should be designated as more important than another.
3. AHRQ would like input on how to target investments within high-priority areas. For example, should AHRQ focus on: a. Specific ages/stages or apply AHRQ's investments equally across the lifespan?	There is a vast body of literature to identify populations with special needs. Areas of focus need to be established rigorously, not just chosen because of a seemingly "obvious" need.
b. Transitions in care?	There is a need to define transitions of care (TOC). Again, similar comments apply to transitions: establish the need in a rigorous way. PCORTF can play a significant role to help nurture the development of the ecosystem and the co-design process with patients. One of the common themes observed in the 2021 AMIA TOC workshop https://amia.org/education-events/amia-2021-annual-

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	symposium/program?search_api_fulltext=&page=3 is that the TOC setting is at the end point of need , and many of the early-stage interventions could have taken place but failed to make an impact.
4. AHRQ would also appreciate suggestions for applying the strategic framework. For example: a. How can AHRQ improve the dissemination of patient-centered outcomes research evidence to decision-makers at the local, State, and Federal levels?	Implementation science is pointing increasingly in the direction of building worthwhile goals into research programs from the outset. Excellent research should have a path to making patients, groups, and communities better.
b. What targeted investments could AHRQ make to sustain progress towards the strategic framework's desired outcomes?	Move towards funding "dual" programs that build in an implementation component addressing an identified priority alongside any research goals. Prioritize research that contains a sustainability plan.
c. What AHRQ PCORTF investments could help improve healthcare provider trust, well-being, and retention?	There is a need to support micro-initiatives to combat burnout. Provider trust, well-being and retention will not be solved in one fell swoop, but through small innovations that become "bright spots" and beacons for dissemination. Columbia University, Vanderbilt University Medical Center, and AMIA, with support from the National Library of Medicine, convened the 25x5 Symposium of decision-makers and influencers representing patients, clinical settings, academia, industry, government, payers, and professional organizations, to establish strategies and approaches to reduce documentation burden on U.S. clinicians by 75%. AHRQ should consider these initial proceedings and review focal areas.
5. How can AHRQ have the greatest impact and success at achieving the vision and mission of the strategic framework? a. What is the most effective way to ensure the *sustainability* of initiatives that seek to enhance the integration of patient-centered outcomes research findings into practice?	As noted above, ensure that funded research has a clear, visible path to implementation. Recognize instances where the claimed "patient-centeredness" or the implications for improved human health are superficial. Research should utilize resources available outside of the research program. Research outcomes must be shared with the populations that were researched.
b. What complementary partnerships and collaborations (both public and private) would increase the impact of AHRQ's PCORTF investments?	AHRQ should partner with professional and patient interest organizations in the evaluation of proposals. This would provide greater transparency and a more evenly spread base of support.
c. What will be the best way of measuring progress and the overall impact of AHRQ's PCORTF investments?	Concrete quantitative and qualitative measures. E.g., How much funding has gone to institutions serving underserved populations? How much of that funding has gone to researchers from those

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	communities? Harvest data from APIs available as a requirement of 21st Century Cures Act regulations.
6. Is there anything else you would like to share regarding the strategic framework?	