

April 19, 2022

Request for information: AHRQ's proposed patient-centered outcomes research trust fund strategic framework.

Dear AHRQ,

On behalf of the IVI Foundation, parent company of the Innovation and Value Initiative (IVI), thank you for the opportunity to provide feedback on AHRQ's Strategic Framework to Guide AHRQ's PCORTF Investments. We appreciate AHRQ's thorough approach and look forward to learning more about its operational plan.

IVI is a 501(c)(3) nonprofit research organization committed to advancing the science, practice, and use of value assessment in healthcare to make it more meaningful to those who receive, provide, and pay for care. Founded in 2017, the organization includes members from the research, patient, payer, purchaser, clinician, and innovator stakeholder communities. IVI's work emphasizes collaboration and exploration of new solutions that address our common values of patient-centricity, transparency, and vigorous methods enhancement.

IVI is committed to improving the measurement of value and access to the best and most cost-effective healthcare interventions through economic model development, patient-centered research, and convening stakeholders from across the healthcare system to collaborate to improve methods in value assessment. Our principles drive our approach and support our mission to advance the science of value assessment for those who receive and pay for care. We see a significant alignment with AHRQ's focus on training the next generation of healthcare researchers and the dissemination of best practices and patient-centered research. Together, we share a common goal to improve access to equitable, whole-person care across the lifespan.

General Comments

We commend AHRQ for the development of the strategic Framework and appreciate its structure and organization. We also commend the focus on issues of equity and behavioral health. IVI is currently developing an economic model on [major depressive disorder](#) and is launching a health equity initiative that will look at how we can ensure that methods in value assessment improve health equity. As the Framework suggests, both issues thread across the entire health system.

Clearly, since this Framework is designed to guide AHRQ's PCORTF investments, people with lived experience (e.g., patients) need to be at the center of both the framework and your approach. In the upcoming review of the Framework, we encourage AHRQ to approach all revisions through this lens.

We do suggest, if it is within your scope, adjusting the overarching vision to say, "**access to high-quality**, equitable whole-person care across the lifespan." We believe this better reflects the rest of the Framework and AHRQ's mission. In addition, we suggest making the High-Level Goal more concise, such as:

- Improve health-outcomes by promoting access to high-value, evidence-based patient-centered care, with a focus on underserved populations.



In its current form, it includes too many overlapping descriptors. For example, wouldn't high-value, evidence-based care need to be also safe? Further, are there real differences between integrated, coordinated, and team-based care?

This Framework highlights many of the challenges our healthcare system needs to overcome - and we recognize that AHRQ may need to further narrow its priorities. We have three general recommendations for the Framework and then will offer additional considerations.

1. We recommend that AHRQ clearly differentiate its work from other HHS agencies and PCORI. We commend the growing investment in patient-centered research across the agencies. Further, it is imperative that each agency demonstrate both how it is working towards its mission and highlight it can augment and support other agencies without duplicating efforts. As the agency charged with dissemination and education, AHRQ has a unique opportunity to strengthen the work of the rest of HHS, PCORI, and other agencies.
2. We encourage AHRQ (and other agencies) to establish minimum inclusion standards for people with lived experience, especially people from underserved communities, in its research studies and training programs.
3. We also support training programs that foster co-design of research and programs with patients, which may include training both researchers and patients in best practices.

We also encourage AHRQ to engage with patient and community organizations, and research organizations like IVI to ensure that people with lived experience remain at the center of your work.

Clarification of Terms

While we understand that the Framework is designed to be a concise formulation of AHRQ's priorities, desired outcomes, and cross-cutting strategies, it would be helpful to clarify some of the terms either in a glossary or in the operational plan. Many of these concepts have multiple meanings for different audiences or are defined differently across agencies and organizations. For example:

Promoting High-Value Care

While it is difficult for anyone to argue *against* "high-value" care, we do need to clarify value for whom. Traditionally, value has been defined from the clinician or payer perspective, but we suggest, especially for this Framework, that value needs to be explicitly defined in terms of value for patients and family members. By putting patients at the center of the definition of value and of the Framework, it puts in place the impetus to ensure that [patients are at the center of healthcare research and practice](#).

Evidence

There are multiple areas where the Framework uses the term "evidence-based care/services/research." We suggest clarifying what you mean by "evidence." Does it include only clinical trials, or will it also include real world evidence? How will AHRQ establish guidelines about what should be included in decision-making, and how will AHRQ ensure that these guidelines are coordinated with other agencies? We see a significant need for a better understanding of what constitutes evidence and how it can inform decision making.



For both definitions, it is important to clearly articulate the importance of including measures and attributes outside of just clinical measures, and to explicitly raise attention to real world data, observational data, and patient preference research.

Given its mission to disseminate evidence into practice and to help train the next generation of researchers, AHRQ is uniquely situated to bring together different agencies to develop a common road-map and guidance on how to evaluate evidence, especially to ensure that patients are at the center of evidence-generation.

Priorities and Outcomes

In the request for comments, AHRQ includes several questions. While we will not attempt to answer all of them, we do want to comment on several.

Are there any high level priorities more important than others?

While we see each of these priorities as important, Priority D, High-Quality Safe care that is aligned with National Priorities, is broader than the others and really should function as an umbrella priority. Each of the other priorities are part of the effort to drive toward high-quality care.

In addition, we strongly support efforts to prioritize health equity. We also recognize that there is a tension in pulling equity goals into its own category. Doing so elevates health equity as a principle priority, which we wholly support, but it is equally important that it be explicitly incorporated into the pursuit of all other priorities guiding AHRQ's work. Just like high quality care and patient-centeredness, equity is a desired outcome for each of the priorities.

Comments on Identified Desired Outcomes

- **Engagement of underrepresented communities in training and implementation initiatives.** We think this outcome is well within the mission and work of AHRQ, and should be part of all of its dissemination efforts.
- **Co-Design of innovations in care with patients and communities.** We highly commend this desired outcome and encourage AHRQ to look at the recent CHEERS report on economic modeling, our [blog series](#) on the CHEERs report, and the IVI Principles. When developing the operational plan, we suggest AHRQ consider including this desired outcome across its priorities and identify ways to highlight in its dissemination and training programs how patients have co-designed research and care plans. Any program you fund should have a patient-engagement plan and include measures for impact.
- **Transformation of healthcare organizations into learning health systems.** As the leader in training and dissemination, AHRQ is well positioned to help healthcare organizations learn and put patients at the center of their organizations. IVI recently published a [commentary](#) on learning health systems, and we hope it can provide a guide for AHRQ for putting this aspiration into practice.
- **Uptake of new models of primary care, leveraging digital healthcare.** We suggest that AHRQ clarify that the outcome is an uptake of new, evidence-based models of primary care. We also suggest that this fits under the transformation into a learning health system.

Input on how to target AHRQ Investments

AHRQ plays an important role in training future healthcare researchers and in sharing information about new research and programs. We hope that the organization will continue to



build on that expertise. We do think that the PCORTF provides an opportunity for AHRQ to focus its investments to support community-based researchers, especially in low-income communities. In addition, AHRQ may want to partner with PCORI and the National Health Council to train patients and patient groups along with researchers in patient-centered research, especially in under-represented communities. We have noticed that not only do researchers need training on patient-centered research but that people with lived experience need skill development to better understand the research process.

Summary

AHRQ's overall mission is to produce evidence to make healthcare safer, higher quality, more accessible, equitable, and affordable, and to work within the U.S. Department of Health and Human Services and with other partners to make sure that the evidence is understood and used.

As you continue to advance the strategic framework to guide AHRQ's PCORTF investments, this mission should be kept as a focal point. AHRQ can be a connective thread across the many agencies within HHS and beyond to ensure that we are advancing high-quality care.

To augment efforts to promote patient-centered research, we strongly encourage that AHRQ (and other agencies) establish minimum inclusion standards for people with lived experience and people from underserved communities in particular. We also strongly encourage training programs that foster co-design of research and programs with patients, which may include training both researchers and patients in best practices.

Thank you for the opportunity to provide feedback on the Strategic Framework, and we look forward to partnering with you in the future. If you have any questions or would like to discuss our comments in further detail, please contact me at jennifer.bright@thevalueinitiative.org.

Sincerely,

A handwritten signature in black ink that reads 'Jennifer Bright'. The signature is fluid and cursive, with the first letters of the first and last names being capitalized and prominent.

Jennifer Bright
Chief Executive Officer
Innovation and Value Initiative



Suggested References

Bright, J. and A. Balch (March 1, 2022). Health Care Value Through The Lens Of Patients' Well-Being. Available: <https://www.healthaffairs.org/doi/10.1377/forefront.20220228.656900> (final piece in [11-part series](#)). *Health Affairs Forefront Blog*.

Bright, J. Patient Value Is the Root of a Learning Health System. *Am J Accountable Care*. 2021;9(4):34-36. <https://doi.org/10.37765/ajac.2021.88805>

Courtney, C., Phillips, L., Masco, R., O'Hara Levi, S., Bright, J., Eller, J., Hyde, A., Kelly, M. and E. Malik (October 2021). "First-Hand Perspectives in Rheumatoid Arthritis: Insights to Improve Healthcare Research & Value Assessment." Produced by the Innovation and Value Initiative. Available: https://www.thevalueinitiative.org/wp-content/uploads/2021/10/First-Hand-Perspectives-in-Rheumatoid-Arthritis_FINAL.pdf

Husereau D, Drummond M, Augustovski F, et al. Consolidated Health Economic Evaluation Reporting Standards 2022 (CHEERS 2022) Explanation and Elaboration: A Report of the ISPOR CHEERS II Good Practices Task Force. *Value in Health*. 2022;25(1):10-31.

Innovation and Value Initiative Methods Summit: Designing Equitable Measures and Methods for Patient Priorities in Healthcare Value Assessment Proceedings Report (Methods 2022). Produced by the Innovation and Value Initiative. Available: https://www.thevalueinitiative.org/wp-content/uploads/2022/03/2021-Methods-Summit-Report_FINAL.pdf

Linthicum MT, dosReis S, Slejko JF, Mattingly TJ, Bright JL. "[The Importance of Collaboration in Pursuit of Patient-Centered Value Assessment](#)." *The Patient*. August 28, 2020:1-4. Available: <https://link.springer.com/article/10.1007/s40271-020-00446-3>

National Health Council. The National Health Council Rubric to Capture the Patient Voice: A Guide to Incorporating the Patient Voice into the Health Ecosystem. June 2019. Washington, DC. Available from: <https://www.nationalhealthcouncil.org/Patient-Engagement-Rubric>

Principles for Value Assessment in the United States (2021). The Innovation and Value Initiative. Available: https://www.thevalueinitiative.org/wp-content/uploads/2021/01/2021-IVI-Principles-of-VA_FINAL.pdf

Xie RZ, Malik E deFur, Linthicum MT, Bright JL. "[Putting Stakeholder Engagement at the Center of Health Economic Modeling for Health Technology Assessment in the United States](#)." *Pharmacoeconomics*. 2021;39(6):631-638. Available: <https://link.springer.com/article/10.1007/s40273-021-01036-3>