External Stakeholder Report
June 2023

Patient-Centered Outcomes Research Trust Fund (PCORTF)

Agency for Healthcare Research and Quality

Agency for Healthcare Research and Quality Patient-Centered Outcomes Research Trust Fund

External Stakeholder Report

Acknowledgements:

Table of Contents

Acronyms

AHRQ	Agency for Healthcare Research and Quality
ASPE	Office of the Assistant Secretary for Planning and Evaluation
ASTHO	Association of State and Territorial Health Officials
CVD	Cardiovascular disease
CBPR	Community-based participatory research
CHW	Community health workers
CMS	Centers for Medicare and Medicaid Services
DEI	Diversity, Equity, and Inclusion
E-StaR	Embedded Scientist Training and Research Centers
HHS	U.S. Department of Health and Human Services
HRSA	Health Resources and Services Administration
LGBTQIA+	Lesbian, gay, bisexual, trans, queer, intersex, asexual, and other sexualities, sexes and genders
LHS	Learning Health Systems
MODRN	Medicaid Outcomes Distributed Research Network
NAC	National Advisory Council
NACCHO	National Association of County and City Health Officials
NAMCS	National Ambulatory Medical Care Survey
NASEM	National Academies of Sciences, Engineering, and Medicine
NASHP	National Academy for State Health Policy
PBRN	Practice-based research network
PCORTF	Patient-Centered Outcomes Research Trust Fund
PDSA	Plan-do-study-act
PLWMCC	People Living with Multiple Chronic Conditions
RE-AIM	Reach, Effectiveness, Adoption, Implementation, and Maintenance framework
SDOH	Social determinants of health
SDM	Shared Decision-Making
SNAC	Subcommittee of the National Advisory Council
SNOCAP	State Networks of Colorado Ambulatory Practices and Partners
SUPLN	State-University Partnership Learning Network
USPSTF	U.S. Preventive Services Task Force
UPMC	University of Pittsburgh Medical Center
VA	Veterans Affairs

Executive Summary
Overview

This report synthesizes stakeholder input from events and activities to inform the Agency for Healthcare Research and Quality's (AHRQ's) strategic planning process for the Patient-Centered Outcomes Research Trust Fund (PCORTF). It includes public comments that were submitted in response to the PCORTF Strategic Framework Federal Register Notice, the National Academies of Sciences, Engineering, and Medicine (NASEM) PCORTF workshop proceedings, presentations and recommendations from the PCORTF Subcommittee of the National Advisory Council (SNAC), the AHRQ National Advisory Council's (NAC) response to the SNAC report, the Multiple Chronic Conditions Research Summit, The U.S. Preventive Services Task Force (USPSTF), and the Primary Care Research Conference. Below we highlight key themes from stakeholder input. These are followed by ways in which AHRQ responded to external stakeholder input to strengthen the PCORTF Strategic Framework as well as areas for further consideration as AHRQ implements the Framework.

Primary Themes

Meaningful stakeholder engagement
Stakeholders emphasized the need to engage deeply and continuously with key stakeholders throughout the research, planning and design processes of PCOR efforts. This includes participation during formative steps to develop research questions and metrics, and in later stages during dissemination and implementation. When discussing dissemination, stakeholders commented upon who disseminates findings, the channels through which they accomplish this, and tailoring content to specific audiences. Many speakers emphasized the need to return data to communities in an accessible and actionable format and communicate effectively with policymakers.

Several stakeholders also noted that it is important to fund infrastructure that extends beyond project-specific needs to build sustainable engagement. This funding could, for example, support committees that evaluate the potential benefits of research to a community, capacity building for stakeholders and researchers, and continuity of academic-community relationships over time. Several stakeholders also mentioned formalized structures to involve stakeholders throughout the research process, such as community advisory councils, patient advisory groups and a Diversity, Equity, and Inclusion (DEI) committee to review progress on inclusivity in PCORTF efforts.

Accessible language facilitates engagement. Stakeholders indicated that the language used in the framework is not sufficiently accessible. Additionally, stakeholders suggested that defining terms would be helpful. For example, definitions would be helpful for health equity and disparities, underserved populations, social determinants of health, whole-person care, co-design, value, evidence, integrated care, and digital healthcare.

Health equity

As opposed to depicting health equity as its own pillar or standalone priority area, stakeholders suggested it as a cross-cutting strategy or guiding principle that should be applied to all areas of the framework. Additionally, stakeholders suggested that AHRQ embed health equity as an outcome within the priority areas. Stakeholders emphasized the need to highlight structural factors that impact health (e.g., social determinants of health, institutional racism, implicit and explicit bias among providers in their approach to treat diverse populations) and to recognize the community and cultural context in which patients are embedded. They also emphasized the importance of inclusivity, including collecting data from diverse populations. Additionally, participants commented upon the importance of collecting outcomes data to measure equitable impact.

Trust

The importance of trust was mentioned repeatedly and was often framed as trust by communities or groups as opposed to only individuals. Many stakeholders stressed the importance of Shared Decision-Making (SDM) and 'co-creating meaningful care' with patients in achieving whole-person care, and felt it should be explicitly named in the framework. SDM is an important component to build trust with providers.

Cost and affordability

Many stakeholders noticed that cost and affordability are not a focus of AHRQ's strategic planning framework and suggested adding it in addition to quality of care as a patient-centered outcome.

Training and workforce development

Stakeholders discussed the need to train future PCOR researchers and other healthcare professionals to engage meaningfully with communities, including understanding community context and learning how to disseminate research in language accessible to intended audiences. To meet these goals, some stakeholders recommended that community members participate in training researchers to better recognize and increase sensitivity to a community's needs. Stakeholders also noted there is a shortage of

primary care providers and the importance of investing in a robust pipeline of professionals who could further AHRQ's mission, including primary care clinicians.

Evaluating implementation and impact

Many stakeholders emphasized the need to have rapid feedback loops between evaluation and implementation [e.g., plan-do-study-act (PDSA) cycles]. Stakeholders also provided comments on supporting Learning Health System models or approaches that allow for a continuous feedback loop and ongoing learnings to inform how to best adapt or even pivot throughout the design, planning, dissemination, and implementation stages of healthcare improvement.

The PCORTF SNAC provided high-level considerations for outcomes and metrics for investments, including patient-reported outcomes and metrics that assess the extent to which systems have changed in accordance with evidence-based approaches. The subcommittee also noted that implementation science metrics could measure systems change more effectively than more common clinical and patient-focused metrics.

Changes made to the Strategic Framework in Response to External Stakeholder Input

Meaningful stakeholder engagement

- The call for deep and continuous engagement with stakeholders aligns with our guiding principles of being "collaborative" and "stakeholder driven." AHRQ incorporated the concept of deep and continuous stakeholder engagement as a cross-cutting strategy to achieve our goals, such as with patients and their advocates, community organizations, local health coalitions, and others that best represent end users of healthcare improvement.
- In the Framework's cross-cutting strategies, AHRQ initially focused on disseminating evidence to Federal, state, and local healthcare decisionmakers. In response to feedback to return data to communities in accessible and actionable formats, AHRQ plans to disseminate findings back to other types of stakeholders (e.g., patients, communities) as well. This is called out in our cross-cutting strategies.

Health equity

- The Framework now indicates that health equity cuts across all areas of the Framework, including as outcomes within the priority areas.

- AHRQ expanded the PCORTF overarching vision statement to include language that highlights structural and other contextual factors that impact influence patient health. Therefore, the PCORTF vision now reads: "Equitable whole-person care across the lifespan <u>that acknowledges the impact of community and social context on patient health</u>".

Trust
- In response to comments that it is important to build trust at the community level, in addition to other levels, AHRQ expanded the language around trust as follows: "Patient, family, provider, <u>and community</u> experience of care that enhances trust in the healthcare system."
- In response to feedback to include Shared Decision Making (SDM) in the framework, SDM is now explicitly called out as an additional outcome under patient experience of care that enhances trust in the healthcare system: "Improved patient engagement, family engagement, shared decision-making and reported experience of care".

Cost and affordability
- The proposed PCORTF Strategic Framework previously included cost, but not affordability, as part of our evaluation of PCORTF investments. In response to comments on its importance, AHRQ included affordability as part of the overarching goal: "Improve health outcomes by promoting safe, <u>affordable</u>, evidence-based, integrated, coordinated, team-based, patient centered care with a focus on underserved populations."

Training
- AHRQ added language addressing meaningful community engagement to our cross-cutting strategy for training future PCOR researchers and other healthcare professionals: "Train and support the next generation of health services researchers with a focus on team science, <u>understanding community needs</u>, and advancing health equity."

Accessible Language
- In response to calls to increase language accessibility in the PCORTF Framework AHRQ aims to build on its extensive work in [health literacy](#) using simpler and accessible language throughout AHRQ's PCORTF work. To help clarify language in the Strategic Framework, AHRQ included definitions of terms in a glossary.

Additional Key Themes from Stakeholder Input for Further Consideration

Priority research for dissemination and implementation

- Stakeholder input can inform decisions regarding the type of research to disseminate. This could be accomplished by prioritizing funding for the dissemination of research that has demonstrated substantial engagement of key stakeholders.
- Setting benchmarks for funding dissemination of research that focuses on historically understudied populations would help AHRQ meet goals of improving health equity.
- In response to stakeholders' suggestions, AHRQ could prioritize funding to further support Learning Health System models or approaches that emphasize continuous or rapid feedback loops between evaluation and implementation (e.g., PDSA cycles).

Governance and infrastructure

- AHRQ could establish formalized structures (e.g., community advisory councils, patient advisory groups, DEI committees) at the portfolio and projects levels to better incorporate stakeholder voices throughout PCORTF-funded work.
- Funding projects to build capacity beyond project-specific needs and requiring grantees to share funding with community partners would help foster long-term, sustainable engagement.

Metrics

- In planning for evaluating the PCORTF portfolio and projects, AHRQ could work closely with key stakeholders to identify metrics that are meaningful to them and prioritize metrics that assess equitable impact of PCORTF investments and trust in the healthcare system.

Training and Workforce Development

- In response to calls to invest in a pipeline of professionals to further our mission, including primary care clinicians, AHRQ could develop benchmarks for funding to increase training and workforce development in primary care. AHRQ could also combine an increased emphasis on health equity with primary care transformation and workforce development by prioritizing training clinicians who are well versed in health equity issues and actively working in under-resourced communities.
- As recommended by the PCORTF SNAC, AHRQ is actively expanding the scope of our training programs to recruit individuals from multiple disciplines as team

members, practice facilitators, implementation scientists, and change agents in Learning Health Systems. It is AHRQ's goal to build the workforce that can advance PCOR evidence through rigorous research and implementation science. AHRQ is currently working with PCORI to co-fund increased training in this area by establishing Learning Health System Embedded Scientist Training and Research (LHS E-StaR) Centers.

1. Introduction

Overview

This report synthesizes stakeholder input from events and activities to inform the Agency for Healthcare Research and Quality's (AHRQ's) Patient-Centered Outcomes Research Trust Fund (PCORTF) strategic planning process. It includes public comments that were submitted in response to the PCORTF Strategic Framework Federal Register Notice, the National Academies of Sciences, Engineering, and Medicine (NASEM) PCORTF workshop proceedings, presentations and recommendations from the PCORTF Subcommittee of the National Advisory Council (SNAC), the AHRQ National Advisory Council's (NAC) response to the SNAC report, the Multiple Chronic Conditions Research Summit, The U.S. Preventive Services Task Force (USPSTF), and the Primary Care Research Conference. Below are summaries of key themes or key points for each of the documents reviewed. These individual summaries are followed by a section describing our revisions to the PCORTF Strategic Framework that are based upon stakeholder input across data sources.

2. Patient-Centered Outcomes Research Trust Fund (PCORTF) Strategic Framework Federal Register Notice

Data Source Overview

AHRQ released the proposed PCORTF Strategic Framework for public comment in the [Federal Register](#)[1] from February 19 – May 24, 2022. AHRQ received 104 unique responses from a wide variety of organizations and individuals, including academia, industry, clinicians, government agencies, private sector payors and consultants, community and advocacy organizations, and patients.

Summary of Key Themes

1. Overall reaction to the PCORTF Strategic Framework

Overall, stakeholder feedback was positive and supportive of the proposed PCORTF Strategic Framework. At a high level, stakeholders suggested using and communicating a theory of change for this framework and better depicting or explaining how each of the priorities are interrelated. For example, stakeholders thought it would be helpful to explain that achieving some priorities may rely on achieving other priorities. Several commenters also recommended aligning priorities and strategies (or communicating where they align) with other U.S. Health and Human Services (HHS) agencies where feasible to maximize impact on the healthcare system.

2. *Refine language: Define terms, highlight structural racism, and use inclusive and simplified language*

Stakeholders had many specific recommendations regarding the language used throughout the Framework. Many suggested the Framework would benefit from adding definitions for key terms, such as health equity, disparities, underserved populations, whole-person care, co-design, value, access, evidence, integrated care, digital healthcare, and chronic illness, and clarifying the intended audience or end users. Stakeholders suggested providing a clear definition of (or direct link to) AHRQ's priority populations and using a consistent term to refer to them. To assist with this, stakeholders suggested using and linking to definitions and terms from other sources such as the Robert Wood Johnson Foundation or other HHS agencies (for example, to define 'national priorities'). Clear definitions and linkages would help justify the evidence-based priorities and strategies, such as digital health and team-based care, included in the Strategic Framework. Stakeholders acknowledged the potential need for the Framework to remain at a higher level and suggested these terms can be clarified later in a more detailed strategic and/or operational plan.

Stakeholders felt an explicit call-out of structural racism was missing from discussion of health equity. This feedback complements related suggestions to replace the term 'underserved populations' with a term that shifts blame away from communities and acknowledges the root cause of health inequities. Examples of such terms include 'systematically under-resourced' and/or 'structurally disadvantaged.'

Another recommendation was to use and encourage inclusive language wherever possible. For example, provider-neutral language (i.e., generically refer to "clinicians" as opposed to referring to specific roles such as doctors, nurses, etc.) would encourage buy-in from clinicians of all types and underscore the focus on team-based care. Stakeholders suggested adding tribal clinicians and their patients as participants and end users of the Framework to improve inclusivity.

Finally, some stakeholders indicated the Strategic Framework is not public-friendly and recommended using plain language or providing more resources and definitions to clarify its meaning.

3. *Health Equity: Make equity a cross-cutting strategy and embed as an outcome in all priorities*

Overwhelmingly, stakeholders supported the focus on health equity in the PCORTF Strategic Framework. They suggested that it be added as a cross-cutting strategy or

guiding principle to approach all work with a health equity lens. Additionally, they suggested that AHRQ embed health equity as an outcome within all priorities.

Stakeholders underscored the need to design and implement strategies in collaboration with community members who would be affected by initiatives to reduce inequities. They saw this engagement as essential in every aspect and step of the research process, from determining research priorities and questions, study design, and implementation, to analysis, reporting, translation, and dissemination of findings. Partnering with community members could help increase impact and avoid unintended consequences of interventions. For example, within the digital health strategy, electronic technologies can be an important tool and have the potential to reduce some disparities in access. However, they could unintentionally increase inequities in some cases due to factors related to the social determinants of health. These factors may include lack of reliable Internet or e-technology access in rural areas, among homeless populations, and lower income populations.

Stakeholders stressed not only continuous participation, but equal participation. They suggested empowering communities with lived experiences relevant to topics of interest to be equal partners in the research or implementation process. Towards this end, they recommended making data publicly available and easily digestible whenever possible and building community research capacity by supporting education on health, digital, and data literacy and the research process itself. This involvement can also contribute to ensuring culturally appropriate care to communities and thus increased trust in the healthcare system, a priority area of the Framework. Some stakeholders also felt that the Framework should explicitly prioritize reducing power differentials between researchers and communities.

Many stakeholders asserted that it is crucial to prioritize funding/incentives for community engagement as well as disseminating PCOR evidence in which researchers partnered with diverse, trusted, and reputable community-based organizations. Stakeholders also suggested prioritizing disseminating research that uses community-based participatory research (CBPR) over other types of research.

4. *Patient engagement and whole-person care: Fostering shared decision-making and consideration of mental and behavioral health, substance use, and social determinants of health (SDOH)*

Similar to community engagement, stakeholders recommended including patient engagement as a cross-cutting strategy or principle rather than as a desired outcome. Many stressed the importance of Shared Decision-Making (SDM) and 'co-creating

meaningful care' with patients in achieving patient-centered and whole-person care and felt it should be explicitly named in the Framework. Specifically, stakeholders recommended supporting patient capacity and empowerment to communicate, negotiate, and navigate the healthcare system. They acknowledged the tension between traditional clinical outcomes and outcomes most valued by patients and suggested including both as the Strategic Framework is operationalized and evaluated. Other indicators of patient-centeredness could include reduction of complexity (such as administrative burden), patient autonomy or empowerment in decision-making, and use of digital self-monitoring tools, including patient-reported outcomes (PROs).

In addition to patient-centeredness, stakeholders agree that achieving whole-person care means addressing mental and behavioral health, substance use, and social determinants of health (SDOH), and thus requires using expanded health teams, including greater participation by community health workers, social workers, and many other disciplines and provider types. Many comments emphasized the Framework, in its pursuit of whole-person care, lacks the necessary inclusion or integration of public health with human and social services systems, as both are positioned to impact non-medical determinants of health. Research and dissemination efforts involving partners from these sectors would improve sustainability of this work by helping to address root causes of inequities outside of the medical field alone.

5. *Prioritizing populations according to life phase and barriers to accessing care*

The majority of stakeholders advocated addressing health and healthcare across the lifespan. However, several made the case for prioritizing health during specific phases of the life course. Concerns about health equity and impact drove these comments. Many stakeholders explained that focusing investments on maternal and child health would have the greatest impact, or 'bang for the buck,' on prevention and health equity by starting children on a more positive health trajectory beginning in the early phases of life. Conversely, many also recommended prioritizing aging populations that are more impacted by chronic conditions (including having multiple chronic conditions) than others and were especially impacted by the COVID-19 pandemic. Importantly, some noted that by including care for people with chronic conditions as a priority, aging populations will be a focus simply because they are more likely to have chronic conditions and are more likely to interact with the healthcare system than other population groups.

Stakeholders also commented upon the need to prioritize vulnerable and marginalized populations that have greater barriers to accessing care, including populations in rural locations, uninsured and underinsured patients, populations with language barriers, and

lesbian, gay, bisexual, trans, queer, intersex, asexual, and other sexualities, sexes and genders (LGBTQIA+) populations. Here too, concerns about health inequities and unequal access to care drove these comments. The Strategic Framework is intended to prioritize these populations, yet some argued that a focus on chronic disease leaves them out since they tend to have difficulties accessing basic primary care and thus may not be diagnosed with a chronic condition. Therefore, some comments suggested adding a priority to address or increase access to healthcare for these populations to get them 'in the door.' As the Framework is operationalized, this priority could include ensuring sufficient primary healthcare workers, including healthcare 'extenders,' who are willing and able to serve all patients regardless of insurance status, are placed in the right locations.

6. *Key dissemination partners: payors, patient advocates, community-based organizations, professional groups, and other Federal agencies*

Stakeholders recognized that success of the PCORTF Strategic Framework and investments will be impacted by outside influences, including the regulatory environment and public and private payor policies at national, state, and local levels (especially Medicaid programs). Stakeholders recommended that PCOR dissemination activities should include payors as partners whenever possible to advocate for the most effective strategies to implement PCOR evidence and achieve the Framework's desired outcomes. Additionally, stakeholders identified patient advocates and community-based advocacy organizations or coalition groups as particularly influential trusted messengers in educating policymakers on what communities need most, and suggested AHRQ consider funding capacity-building of these skills. In addition, professional groups representing clinicians of all types would be helpful partners to increase influence on policymakers, along with Associations {such as the National Academy for State Health Policy (NASHP), AcademyHealth, the National Association of County and City Health Officials (NACCHO), the Association of State and Territorial Health Officials (ASTHO), etc.}, and learning/research/policy networks and institutes {the State-University Partnership Learning Network (SUPLN), and the Medicaid Outcomes Distributed Research Network (MODRN)}. Stakeholders also recommended partnering with other Federal agencies such as the Centers for Medicare and Medicaid Services (CMS), the Health Resources and Services Administration (HRSA), and Veterans Affairs (the VA) to disseminate information, as well as using various forms of social media to reach the public directly.

7. *Digital Health and implementation: Iterative cycles, improved interoperability standards, cross-sector data sharing, assessing digital health impact via patient-reported outcomes, and streamlining technology*

Beyond disseminating information to partners, stakeholders recommended establishing mechanisms by which research is informed or co-designed with feedback from partners in an iterative cycle, aided by digital technology. Stakeholders recommended supporting the development or more widespread adoption of interoperability standards to more easily collect and analyze data and ultimately create better clinical guidelines. Better integration and bi-directional sharing of data across sectors would help inform policy, drive prevention and disease management efforts, and support community resource information sharing. Some feedback mentioned that adding or expanding clinical registries would be useful in this effort as well. Funds would be needed to modernize health data infrastructure to achieve this data ecosystem.

Many comments focused on the importance of assessing the impact of digital health using patient-reported outcomes. This is especially important to address health equity, as certain tools, such as patient portals, can have the effect of increasing inequity by placing more responsibility on patients. Commenters implored AHRQ to ensure equitable distribution of funds for assessing digital health impact so that providers with fewer resources or located in more underserved areas can realize the benefits from these tools without creating unintentional inequities. Additionally, commenters suggested streamlining technology infrastructure setup by grantees (for example, by establishing an approved vendor list) to support health data modernization and to allow projects to get underway more quickly and the resulting tools to be used beyond the life of the grant.

8. *Capacity building: workforce pipeline, provider training and wellness, and learning health system infrastructure*

Beyond those noted above, stakeholders suggested additional capacity-building priorities: a robust workforce pipeline, provider training and wellness, and a learning health system infrastructure. Many comments applauded the Strategic Framework's inclusion of provider retention, wellness, and training, and conveyed that an upstream workforce pipeline should be considered as well. For example, targeting investments to build the behavioral health and community health workforce would contribute to health teams' ability to address social determinants of health and deliver whole-person care. Commenters also recognized the shortage of primary care providers as compared to other specialties and implored AHRQ to incentivize providing primary care and grow the primary care clinician pipeline. For example, stakeholders recommended reducing

minimum entry requirements for certain professions and supporting subspecialties that require less training. (Note: these types of activities fall outside of AHRQ's PCORTF authorized training activities.) Related to the health equity priority, stakeholders recommended special pipeline and empowerment programs to support underrepresented minorities as research leaders and clinicians of the future so that providers will be representative of the communities they serve.

To retain providers already practicing, stakeholders suggested prioritizing funding towards dissemination of evidence on factors influencing provider retention, resilience, and wellness, including greater representation of diverse backgrounds. Additionally, disseminating best practices around reducing administrative and measurement burden should be prioritized.

Stakeholders pointed out that building capacity among providers in different areas will contribute to achieving outcomes across the Strategic Framework. Stakeholders recommended funding interprofessional continuing education or other training programs and technical assistance on community engagement/co-design and community-based participatory research (CBPR); culturally responsive care; SDM and patient-centered care/methods; social determinants of health, including environmental health, informatics, data and measurement; conducting reproducible research; and translation of research into practice and policy. They also insisted on evaluating the effectiveness of these trainings and continually adjusting as necessary.

In the spirit of continuous improvement, many stakeholders provided comments on supporting Learning Health Systems (LHS). Some stakeholders cautioned against disregarding similar initiatives and groups such as practice-based research networks (PBRNs) and state-wide initiatives that are providing valuable contributions toward shared goals.

9. *Trust in the healthcare system*

Stakeholders posited that addressing other priorities in the Framework could lead to increased trust in the healthcare system which, in turn, could help reduce provider burnout, better engage communities throughout the planning process, and ultimately work towards whole-person care. However, some stakeholders noted important components related to trust were missing from the Framework, including the impact of politics on health (e.g., the politicization of COVID-19, including distrust of authorities and vaccines), the spread of misinformation via social media, and the replication crisis in science. In addition, stakeholders emphasized the need to develop ways to measure trust and assess progress in this area.

10. *Affordability and access*

Many stakeholders commented on the lack of focus on cost or affordability in the Strategic Framework. Stakeholders noted that cost can have a huge impact on the healthcare system, as well as on the individual seeking care. For example, costs to implement new practices can be very prohibitive when primary care is already on shaky ground. Primary care providers may need grant funding or better alignment of reimbursement from payers specifically for this work. Health equity might be at stake if new models of care delivery are too costly for some populations and access to care is reduced. In its current state, the high costs of the U.S. healthcare system results in many medical bankruptcies and cost-related medication nonadherence or underutilization for individuals. Stakeholders encouraged AHRQ to feature cost and affordability more prominently in the Strategic Framework.

11. *Payment models*

Similar to cost, stakeholders noted the absence of value-based care and payment reform and advocated for its inclusion in the Framework. Commenters indicated that payment reform that incentivizes higher value would impact other priorities and outcomes, including provider retention and well-being due to expanded health teams and increased flexibility in care delivery. While efforts are underway to transition to value-based payment models, progress is slow. Stakeholders urged AHRQ to identify efficiencies, eliminate clinical processes or care approaches that are not helpful, and identify new practices that should be implemented to increase value.

12. *The COVID-19 pandemic*

Several stakeholders noted the Framework did not include mention of the pandemic. They suggested incorporating the risk of infectious disease and/or "improved emergency resilience" into the Framework as an additional priority area or a cross-cutting strategy. Noting the pandemic's impact on lack of trust in the healthcare system, stakeholders encouraged AHRQ to consider it under the 'enhancing trust' priority.

13. *Evaluating the PCORTF Strategic Framework*

Comments detailed many ways for AHRQ to measure progress toward the Framework's desired outcomes and demonstrate transparency and accountability while doing so. Stakeholders agreed that a comprehensive evaluation strategy will require generating a set of measures that are informed by PCOR and are meaningful to both patients and providers, including health, economic, and equity impacts, with a target or benchmark to track against. Other suggestions included convening a Diversity, Equity, and Inclusion (DEI) committee to review progress on inclusiveness among grant programs; utilizing an AHRQ National Advisory Council (NAC) sub-committee on health equity; and publishing

regular progress reports. Stakeholders suggested surveying the public and funded researchers to help these efforts, especially to assess community engagement. Stakeholders also recommended evaluating the effectiveness of PCORTF-funded healthcare clinician training in clinical practice, especially around providing culturally appropriate care.

14. *Next steps: respond to stakeholder feedback along the way and clarify AHRQ's mandate*

Stakeholders insisted that AHRQ employ an iterative strategic planning and evaluation process, responding to stakeholder input along the way and incorporating feedback for continuous quality improvement. Several comments recommended that AHRQ clearly differentiate its PCORTF work from other HHS agencies and PCORI, which may be substantiated by the many comments suggesting AHRQ conduct research and produce PCOR evidence, rather than focusing on its dissemination as mandated. To this end, stakeholders suggested a targeted public relations and marketing campaign to educate the public and help sustain progress towards the Strategic Framework's desired outcomes.

3. National Academies of Sciences, Engineering, and Medicine (NASEM) workshops

Data Source Overview

The National Academies of Sciences, Engineering, and Medicine's (NASEM's) Board on Health Care Services hosted four virtual public workshops on behalf of AHRQ between June 9 and July 6, 2022. The overall goal was to explore ways to accelerate the use of PCOR findings in clinical practice to improve health and healthcare. Subject matter experts were invited to present and participate in panel discussions at each workshop.

The statement of task specified the following four priority topic areas.

1. Ways to revise and improve AHRQ's proposed strategic plan, priorities, and strategies to make them clearer and more likely to lead to funding high-impact and complementary projects while being consistent with the congressional mandate for investing funds from PCORTF.
2. Ways to measure progress and the effect of AHRQ's PCORTF investments as a whole on meeting our goals in the near, short, and long term.
3. Ways to better align priorities and strategies and to create complementary collaborations between the agencies charged with using PCORTF to improve patient-centered outcomes research and practice to increase the impact of AHRQ's PCORTF investments and their potential to sustainably reduce disparities.

4. Ways AHRQ can apply communication science to improve dissemination of evidence, gaps in evidence, and policy gaps to inform health policies and decision makers at local, state, and Federal levels.

The proceedings were detailed in the following report: *Accelerating the Use of Findings from Patient-Centered Outcomes Research in Clinical Practice to Improve Health and Health Care: Proceedings of a Workshop Series*[2] (2022). Arbor Research coded the data in the report and developed a summary of primary themes across workshops, which we describe below. Where illustrative, we provide references to individual speakers.

Summary of Key Themes

1. *Deep and continuous stakeholder engagement: essential to health equity*

A prominent cross-cutting theme across workshops was the importance of engaging key stakeholders deeply and continuously throughout the research process. As defined by workshop speakers, deep and continuous engagement involves partnering with stakeholders to make decisions throughout the entire research process, including developing research questions and metrics, implementing projects, and interpreting and disseminating findings. Speakers most often discussed engaging with communities, but also patients, family members, and other stakeholders. This approach is embodied in the phrase "Nothing for us, without us," which Professor Donald Nease from the University of Colorado Anschutz Medical Campus relayed as a key principle followed by the Colorado Clinical and Translational Sciences Institute (CCTSI) and the State Networks of Colorado Ambulatory Practices and Partners (SNOCAP) PBRNs. Others used terms such as "power-sharing" and "co-creation" to characterize a research paradigm in which community members and other key stakeholders are genuine research partners as opposed to purely end-users. This research approach is consistent with tenets of community-based participatory research, which some speakers mentioned. Speakers thought that deep stakeholder engagement would improve the relevance and impact of research on end users and more successfully advance health equity. An emphasis on engagement is also discussed in the context of many of the subsequent topic areas below.

2. *Trust: essential for partnerships and implementation*

Trust was discussed many times throughout the workshop proceedings. Speakers emphasized the need to build trust in order to build and sustain research partnerships with communities, including by listening to communities to hear what matters to them, iterating approaches based upon community input, creating leadership roles for community members, and disseminating information through trusted members of communities. Speakers noted that it takes time to build such relationships. Mr. Silas

Buchanan from the Institute for eHealth Equity noted the leaders of faith-based and community-based organizations are important implementation partners because they are embedded in underserved communities and are known and trusted by members of these communities.

3. *Implementation: the importance of understanding context and lived experiences*

Several speakers emphasized the importance of local context and lived experiences of patients when implementing interventions. While research is meant to be generalizable, implementation is local. Thus, researchers must pay attention to local factors that impact implementation. Engaging with communities early in the research process can increase the relevance of research during the implementation phase since communities have knowledge of these local factors. Professor Andrea Graham from Northwestern University's Feinberg School of Medicine discussed the importance of understanding context when developing digital tools. Often when digital interventions are applied in real-word settings, they encounter implementation challenges such as low rates of use and retention among patients or failed integration within systems of care. Developers must design these tools to match patient needs and clinician workflows through pragmatic designs.

Dr. Shreya Kangovi from the Penn Center for Community Health Workers and University of Pennsylvania Perelman School of Medicine stressed that community health workers (CHWs) can play an important role in equitable implementation of patient-centered outcomes research because they have a deep understanding of both community context and the lived experiences of patients. They can address health equity at multiple levels, including by acting as a critical link between providers and patients, coaching patients in behavior change, and engaging in policy advocacy. Kangovi and colleagues developed the IMPaCT program, which includes a stepwise process to recruit, train, and deploy CHWs.

4. *Dissemination: identifying the right partners, channels, and content*

Speakers offered many thoughts on how to improve dissemination of research to maximize reach and impact. This included comments on who disseminates findings, the channels through which they accomplish this, and tailoring content to specific audiences.

They suggested that it is important to partner with community members to deliver messages, such as having a "local champion" aid in dissemination. PBRNs and regional health connectors can also disseminate evidence effectively because they have strong community relationships. Many speakers emphasized the need to return data to communities in a format that is accessible and actionable. For example, dissemination

should go beyond publication of results in academic journals and presentations at academic conferences to other channels, including social media, community media, and policy briefs.

Community partners can also help to develop content to ensure that it is culturally appropriate for certain intended audiences, available in languages other than English, and avoids jargon for non-medical and non-academic audiences. Some recommended creating messaging around values and beliefs to increase resonance with target audiences. Dr. Manisha Sharma from CentiVox Media Group noted that cross-sector collaborations are important in the dissemination process because diverse stakeholders can help communications departments translate research findings into information that resonates with target populations. Professor Jonathan Purtle from New York University's Global Center for Implementation Science discussed key phases to increase the efficacy of dissemination to policy makers. The first phase is formative audience research, which entails broad, descriptive research to understand a target audience of policy makers. It aims to gain information about the intended audience's awareness of the problem that a given policy is seeking to address and to determine policy makers' attitudes about a specific evidence-supported policy. This information is then used to inform how to design dissemination materials and the channels and sources through which to distribute them. The second phase of dissemination research is audience segmentation research, which involves collecting data to inform how to best tailor materials to specific groups of policy makers and legislators within a given target audience.

5. *Training students and professionals to engage with stakeholders*

Speakers noted the need to train students to engage with stakeholders more meaningfully. This includes training medical and public policy students to communicate effectively beyond journal publications. The Charles R. Drew University of Medicine and Science has a community faculty track where local residents affiliated with a community of interest or a nonprofit agency serve as faculty to give students community perspectives. They teach courses on topics such as principles of community engagement, capacity building, place-based health, organizational development, and social justice. Additionally, they conduct research, participate in the admissions review process and support dissemination efforts. The Pardee RAND Graduate School also engages community members in academia. Doctoral students are required to have a community partner on their dissertation committee.

Speakers also emphasized the need to train professionals who are already in the workforce so that they can engage more meaningfully with communities. For example, Gaglioti suggested that career development awards should include a training activity on patient and stakeholder engagement in research and that it would be valuable for

patients or community members with lived experience in an area of interest to serve as mentors on career development awards. Speakers also suggested that researchers and healthcare professionals should receive training to communicate findings via radio, television, and social media. Moreover, it was suggested that AHRQ could develop a curriculum that would educate clinicians and researchers to influence policy, such as by learning how to write a policy brief and cultivating their ability to think about research questions that can affect policy change.

6. *Infrastructure for governance and engagement*

Several speakers mentioned the need to have formalized structures to involve stakeholders throughout the research process, such as community advisory councils and patient advisory groups. Several speakers also noted that it is important to fund infrastructure that is not project-specific to build sustainable engagement. This funding could, for example, support committees that evaluate the potential benefits of research to a community, capacity building for patient and stakeholder advisers and researchers, and continuity of relationships over time.

7. *Data collection and access: recognizing needs of end users, using qualitative approaches, collecting data to measure equitable impact, and increasing external validity*

Several speakers recognized that there are many end users of data, including clinicians, policymakers, communities, patients, community-based organizations, patient advocacy organizations, researchers, and staff from Medicaid agencies. Speakers suggested researchers should consider input from the end users of data regarding their data access and utilization needs. For example, by understanding the type of data that policymakers need to change policies, researchers can structure their research to collect this data. Some speakers also noted that community partners should help to develop metrics that are meaningful to them and that can address health equity. Dr. Gary Puckrein from Minority Quality Forum said that limited access to healthcare data contributes to health inequity. He suggested AHRQ, the Office of the Assistant Secretary for Planning and Evaluation (ASPE), and PCORI could collaborate to democratize access to healthcare data and proposed building a "community data lake" that would give communities access to the data and the analytical capabilities to make use of the data.

Numerous speakers mentioned the importance of collecting qualitative data, which can provide important context for quantitative data. This includes affording a deeper understanding of factors impacting communities, how communities respond to these challenges, and the effects of interventions. Personal narratives, such as stakeholder stories, can also increase interest among policymakers and media and thus increase the impact of research findings.

Many speakers commented upon the importance of collecting data to measure equitable impact. Dr. Gaglioti from The Metro-Health System and Case Western Reserve University suggested that it is important to prioritize and require equity impact measurement in comparative effectiveness research that measures inequities and evaluates the impact of interventions on reducing them. Professor Rachel Shelton from Columbia University discussed the utility of the Reach, Effectiveness, Adoption, Implementation, and Maintenance (RE-AIM) framework to address equity in implementation, bringing transparency and accountability to the process. The framework examines who is reached, in which settings, and the extent to which the intervention is successfully implemented and maintained over time in specific populations and settings.

Finally, Professor Alisa Stephens-Shields from the University of Pennsylvania Perelman School of Medicine emphasized that it is essential to collect data from diverse populations to assess impact to improve external validity. If researchers do not evaluate the impact of interventions in representative trial sample groups that represent the full range of individuals in the target population, they may overestimate or underestimate the effects of the dissemination and implementation project in the target population. Professor Lynn Blewett from the University of Minnesota emphasized the need for reliable, self-reported data on race and ethnicity. This data can help Medicaid programs to measure social determinants of health and address health equity.

8. *Iterative research approaches*

Professor George Rust from the Florida State University College of Medicine and the Lyonne County Health Department and Dr. James Schuster, Chief Medical Officer for the University of Pittsburgh Medical Center (UPMC) and a member of the PCORI Board of Governors both noted the value of using plan-do-study-act (PDSA) cycles. As opposed to conceptualizing translation, dissemination, and implementation as part of a linear process, a PDSA cycle treats these as simultaneous processes. This approach facilitates learning and allows researchers to change research interventions rapidly in response to feedback. Professor Tamar Krishnamurti from the University of Pittsburgh and Dr. Krisda Chaiyachati from Verily Health Platforms and the University of Pennsylvania stressed the importance of being iterative when building digital tools for healthcare, such as apps and text message–based programs for patients. Researchers must be able to incorporate improvements based upon user feedback.

4. Subcommittee of the National Advisory Council (SNAC) Report

Data Source Overview

The *Interim Report of the Agency for Healthcare Research and Quality (AHRQ) National Advisory Council Subcommittee on the Patient-Centered Outcomes Research Trust Fund (PCORTF) Strategic Framework and Future Activities*[3] highlights the PCORTF SNAC's (subcommittee of the National Advisory Council) comments on the Strategic Framework and AHRQ's investment of its portion of the PCORTF. The SNAC was established to provide recommendations to the National Advisory Council on the strategic plan that will guide AHRQ's PCORTF investments over the 10-year reauthorization period. Some of the themes that came up during discussion were the advantages of working with other Federal agencies and outside organizations across the portfolio of PCORTF work, the need to advance health equity and patient and family engagement, and debate on the objectives and methods for evaluating PCORTF investments. The PCORTF SNAC offered suggestions for the following topics of interest: health equity, portfolio design, training, dissemination and implementation, partnerships, cross-agency collaboration, primary care, outcomes and metrics, and next steps.

Summary of Recommendations

1. Health equity

The PCORTF SNAC recommended that AHRQ focus on "safety-net" settings, which are places that provide care for a disproportionate number of people who experience health disparities. The subcommittee recommended defining these settings using characteristics of the community and the populations they serve rather than organizational type.

The PCORTF SNAC also recommended that AHRQ prioritize addressing equity in patient experience, clinical outcomes, and healthcare access across populations in each of the work areas. The subcommittee recommended including stakeholders in all phases of funding, analyzing project portfolios, and taking equity into account at each level of the design process in order to ensure health equity is prioritized within the overall portfolio and AHRQ's administrative process.

2. Portfolio design and implementation considerations

In support of streamlining portfolio design and implementation processes, the PCORTF SNAC suggested combining dissemination and implementation with training efforts within the same structure, and that AHRQ refer to lessons learned from prior healthcare quality improvement efforts led by other Federal agencies. Additionally, the PCORTF SNAC suggested allocating time and funds to focus on patient and care provider

perspectives in portfolio design to identify components of care that are most desired, noting that more customizable, holistic goals and measures that are tied to quality of life might be of greater value to patients than disease-specific metrics.

3. Innovations in training

The PCORTF SNAC made a number of suggestions to improve and maximize the impact of training models. For example, the SNAC suggested using training programs as opportunities for trainees to form and strengthen strategic partnerships and recruiting and supporting trainees through channels such as hospital and professional associations. They also recommended measuring trainees' success in policy and clinical impact and reach of their work rather than solely assessing trainees based on academic publications to facilitate more robust training and retention experiences. The SNAC also recommended expanding the scope of training programs to recruit individuals pursuing careers in Learning Health Systems (LHS) and research and implementation science to broaden the range of expertise. These recommendations are encompassed by the Framework's cross-cutting strategies for achieving desired outcomes to "train and support the next generation of health service researchers with a focus on team science and advancing health equity".

4. Innovations in dissemination and implementation

The PCORTF SNAC considered potential benefits of designing one or more large-scale initiatives and focused on behavioral health integration in primary care. The SNAC made several recommendations for maximizing the impact and effectiveness of a large initiative, including selecting organizations for lead roles regionally and based on the organizational attributes. The SNAC also made suggestions related to specific behavioral health integration activities, such as implementing measurement-based care protocols for treating behavioral health conditions, defining the effective elements of behavioral health integration models for implementation, evaluating use of an accountability method, supporting equitable access to tools and the Internet, and assessing digital health literacy for patients and staff.

5. Potential partnerships

The PCORTF SNAC explored opportunities and methods for AHRQ to expand partnerships with organizations that are not part of the Federal Government. They suggested partnership on an individual- and community-level, which could be achieved through PCORI's existing structures, to ensure awareness of patient and family priorities. Relatedly, they suggested exploring partnership models inclusive of clinical delivery systems, state Medicaid agencies, and community-based organizations to disseminate clinical best practices and engage with public and elected officials at the state level in the design of policies and payment systems.

6. Cross-agency collaboration

The subcommittee made various recommendations regarding cross-agency collaboration to increase impact of AHRQ PCORTF investments and promote alignment and synergy across the scope, authority, and expertise of other Federal agencies. The SNAC suggested AHRQ could accomplish this by aligning PCORTF work with other HHS agencies' priorities to promote more opportunity for collaboration. AHRQ would be better positioned to collaborate with other agencies, improve financial sustainability, and ultimately change care processes to address health inequities if it engaged in specific actions, such as working with CMS and other public and private payors to develop and implement financial reforms that would better align healthcare payments with the essential characteristics of high-quality care.

7. Challenges in achieving comprehensive primary care

Given the limitations of implementing and maintaining more extensive and robust primary care models in the current environment, the subcommittee explored strategies for improving and achieving comprehensive primary care. Recommendations made by the PCORTF SNAC focused on forming relationships and communicating with decisionmakers to disseminate information about outcomes that were successfully achieved and the extent of necessary resource investment for success. They also recommended defining AHRQ's role in addressing personnel and budgetary constraints to primary care reform.

8. Outcomes and metrics

While the subcommittee reviewed outcomes and metrics for PCORTF investments at a general level, the members were unable to offer specific recommendations given the portfolio of work's current stage. The PCORTF SNAC provided high-level considerations such as including patient-reported outcomes, articulating the scope of behavioral healthcare that the initiative intends to incorporate into primary care, and defining outcomes and measures that assess the extent to which systems have changed in accordance with evidence-based approaches. The subcommittee added that implementation science might have several advantages, noting that it might offer metrics that could measure systems change more effectively than more common clinical and patient-focused metrics. It might also ensure that patient-centered outcomes and measures are implemented equitably by informing the issue of transitioning from quality measures and outcomes to metrics that can be tailored to patient preferences.

9. Next steps

As the PCORTF planning process moves further, the subcommittee recommended the following:

- Review and provide input on next steps based on the forthcoming compilation of content from this report, from the four workshops held by the National Academies of Science, Engineering, and Medicine, and from the public comment process on the Strategic Framework as published in the *Federal Register*.
- The members could provide input on the portfolio of initiatives and projects as those plans become more specific.
- The subcommittee could also weigh in on bringing more focus to the draft Strategic Framework and provide input to the NAC that would continue to build alignment with Agency and Administration priorities.

5. National Advisory Council (NAC) Meeting

Data Source Overview

The SNAC recommendations were reported to the AHRQ NAC in November 2022 for further consideration and approval to share with the AHRQ Director. A summary and key themes from the [NAC meeting][4] are below.

Summary of Key Themes

1. *Partnerships and diversifying funding recipients*

Generally, NAC members agreed with the SNAC's assessment that building partnerships with players outside of the Federal government will be key to achieving PCORTF goals. In particular, members urged AHRQ to explicitly name employers/purchasers in the PCORTF Strategic Framework and involve them in research, as well as help educate them on the value of implementing best practices. One member also suggested investing in building academic-business research partnerships (for example, by offering a research fellowship that requires partnerships with payors or other private entities). Another way to diversify types of researchers would be to give PBRNs grants that could be integrated in underserved communities. One member noted that it would be helpful to assess the compositions of committees participating in PCORTF activities in terms of sector representation and background.

2. *Patient engagement and evaluation*

One member emphasized the importance of patient engagement via individuals or organizations and highlighted the need to measure healthcare outcomes to assess meaningful impact on patients. Others added that evaluation of implementation and population health outcomes can be interrelated, and should both be embraced by AHRQ as it promotes learning health systems.

3. *Make ambitious investments to transform healthcare*

Members urged AHRQ to use investments to tackle large-scale and long-term issues, rather than the traditional types of one-off research projects that often do not get implemented further. This could involve prioritizing funding for researchers with business and community partnerships and developing best-practice playbooks for equity-focused comprehensive primary care.

4. *Training*

One member suggested collaborating with other Federal agencies to identify synergies in training and to expand interdisciplinary training to reach many kinds of people who are involved in providing care. Trainings should also be offered on grantsmanship to build capacity among non-traditional research participants (non-academics).

5. *Additional research*

NAC members suggested additional topic areas in need of further research, such as:
- How care in non-traditional settings and involving non-traditional players, such as Walgreens or Amazon and Google, influences primary care.
- Primary care teams across geographic settings and fiscal outcomes, including how to mitigate barriers to implementation of best practices.

6. Multiple Chronic Conditions Research Summit

Data Source Overview

The urgent need to establish research priorities and research methodologies on patient-centered, system-based solutions for meeting the needs of People Living With Multiple Chronic Conditions (PLWMCC) served as AHRQ's driving force in organizing the Summit[5] on November 18 and 19, 2020. In addition to PLWMCC research and/or clinical treatment professionals, over 100 participants comprised of patients, caregivers, policymakers, funders, and officials from other Federal agencies provided input.

Prior to the Summit, AHRQ initiated a series of stakeholder engagement initiatives in 2019, including key informant interviews, open forums, and panel discussions, to aid in the creation of a research agenda that would influence future MCC-related funding. Through this process, AHRQ identified three broad domains encapsulating areas of needed MCC research and commissioned three evidence reviews to identify relevant knowledge gaps.

During a May 2020 planning meeting to gain additional feedback on the agenda, participants identified health equity as an important overarching theme and emphasized that future studies would need to address the significant impact of the COVID-19

pandemic on individuals living with MCC, their caregivers, clinicians, and the care-delivery system.

Summary of Key Themes

Below is a summary of themes extracted from the small group discussion sessions held during the Summit to collect specific feedback and suggestions on a future research agenda for AHRQ for transforming care for individuals with MCC.

1. *Implementation: leverage and support innovation in digital health, clinical decision support, and new models of care*

Participants shared input on digital health as a key component of high-value care that could potentially be optimized and operationalized. Participants discussed the ideal way for information technology to support the implementation of care plans for PLWMCC to effectively consider and support their goals of care. They also discussed how technology can be leveraged to build a more expansive ecosystem for PLWMCC. Multi-component initiatives that could utilize digital health as a tool emerged from a different small group session, including the initiative to identify models of care that allow patients and care teams to use new technology to advance coordinated, ongoing, comprehensive care for PLWMCC and assess whether they measurably improve patient-centered and policy outcomes.

Participants questioned how new models for care delivery that make use of new technologies can avoid the associated risks of increasing rather than reducing care fragmentation and disparities in care access and quality, as well as how new technologies could support the collection of patient and population health data and support clinical and shared decision-making about the best course of treatment. Additionally, the use of technology was cited as being crucial to support the initiative to strengthen use of predictive modeling, informatics, and data science to identify those at high risk and rising risk and strengthen clinical decision support and care plan development to address identified risks. The use of rapid-cycle real-world testing to address anticipated implementation challenges for clinicians' sustained use, as well as the investigation of the efficacy and impact of using predictive models to support patient engagement and shared decision-making, were among the initiatives' positive outcomes mentioned by participants.

2. *Implementation and Evidence Synthesis: accelerate uptake of evidence into practice to optimize individual and population health and achieve health equity for all*

The interconnectedness between improving health equity and using evidence-based methods in PLWMCC care delivery and outcomes was consistently mentioned during the Summit. Participants discussed a multi-component initiative to develop a common "operating language" or nomenclature for SDOH and community resources, analogous to the way diseases and medical procedures are coded, and agreed that incorporating evidence-based findings into this type of initiative may help quantify ideas like housing, food security, and environmental safety and enable cross-platform connections between patient demands and practical solutions. Participants also proposed enhancing tools and techniques to better recognize and comprehend the preferences and aims of patients. This could be achieved by identifying strategies and tactics for overcoming obstacles and challenges related to the use of clinical guidelines and evidence-based medicine for PLWMCC, as well as strategies for overcoming obstacles and difficulties related to overspecialization for frequently co-occurring issues, such as consulting a healthcare professional to integrate expert opinions.

7. U.S. Preventive Services Task Force

Data Source Overview

The U.S. Preventive Services Task Force (USPSTF) uses scientific evidence to make recommendations about clinical preventive services that can be delivered or referred from primary care in order to improve our Nation's health. In developing these recommendations, the Task Force evaluates the strength of the evidence and considers the tradeoffs between benefits and harms of a preventive service (e.g., screening tests, behavioral counseling, preventive medications) in people without signs or symptoms. In its 12th Annual Report to Congress (November 2022) entitled *High-Priority Evidence Gaps for Clinical Preventive Services*,[6] the USPSTF calls for more research to address evidence gaps in order to improve the health of children, adolescents, adults, and pregnant people, particularly in Black, Hispanic/Latino, American Indian/Alaska Native, and Native Hawaiian/Pacific Islander communities.

The Task Force identified seven overarching areas as research gaps and subtopics within each area. When comparing the USPSTF research topics against AHRQ's PCORTF Strategic Framework, we find that the following three research gaps are in alignment and mentioned repeatedly: increased uptake of evidence-based preventive services, early intervention and secondary intervention to address chronic conditions (henceforth referred to as Topic 1); advance health equity in underserved populations (Topic 2); and leverage and support innovation in digital health (Topic 3). Additionally, there is one mention of a focus on whole-person care, with attention to social determinants of health (Topic 4).

Key Priority Areas

Below are the seven areas identified by USPSTF. Using Topic areas 1-4 indicated in parentheses, we highlight the intersections between USPSTF priority areas and priority areas in the PCORTF Strategic Framework where applicable.

1. "Behavioral counseling interventions for healthy diet and physical activity for cardiovascular disease (CVD) prevention in adults without known risk factors (Topic 1)

   a. Recruit sufficient numbers of participants from populations disproportionately affected by CVD to understand the benefit of physical activity and dietary behavioral counseling interventions in these populations (Topic 2).

   b. Evaluate best practices for clinicians and patients to navigate known environmental and structural barriers to healthy diet and physical activity (Topics 2 and 4).

   c. Design and test interventions to reduce sedentary behavior. The recent increase in working from home during the COVID-19 pandemic may present an opportunity to perform research on effective interventions that reduce sedentary time.

   d. Develop and evaluate culturally appropriate and tailored interventions that may reduce disparities related to cardiovascular health (Topic 2).

2. Behavioral counseling interventions for healthy diet and physical activity for CVD prevention in adults with cardiovascular risk factors (Topic 1)

   a. Encourage greater consistency and standardization of outcome measures in studies, specifically those for physical activity and diet, to better understand the range of effects and interpret the pooled effects.

   b. Examine the effects of the use of newer technologies, such as wearable activity trackers. In addition, examine the effects of Internet-based resources such as daily caloric intake applications or other low-intensity approaches that may be valuable in low-resource settings (Topics 2 and 3).

3. Behavioral counseling interventions for healthy weight and weight gain in pregnancy (potentially related to Topic 1)

   a. Assess the specific components of intensive behavioral interventions, including the specific content, optimal frequency, length of sessions, and number of sessions needed for an intervention to be effective.

   b. Assess whether interventions should be tailored to promote healthy weight gain in populations of pregnant people of advanced maternal age (i.e., older than age 34 years); adolescents; historically underserved

populations such as Black, American Indian/Alaska Native, and Hispanic/Latino persons; and populations with increased rates of overweight and obesity (Topic 2).

4. Interventions for tobacco smoking cessation in adults, including pregnant persons (Topic 1)

   a. Examine effective components of behavioral counseling, including understanding interventions that provide the greatest benefits to high-risk populations (Topic 2).
   b. Examine whether e-cigarettes increase adult tobacco smoking cessation and the potential harms of e-cigarette use.
   c. Examine newer modalities and remotely delivered interventions (mobile phone apps and internet-based interventions) (Topic 3).

5. Screening for prediabetes and Type 2 diabetes in children and adolescents (Topic 1)

   a. Address the effects of lifestyle interventions, pharmacotherapy, or both for treatment of screen-detected prediabetes and diabetes on health outcomes in children and adolescents, particularly in racial and ethnic groups that have a higher prevalence of diabetes (Topic 2).
   b. Address the effects of screening on health outcomes in children and adolescent populations reflective of the prevalence of diabetes in the United States, particularly in racial and ethnic groups that have a higher prevalence of diabetes (Topic 2).

6. Screening for prediabetes and Type 2 diabetes in adults (Topic 1)

   a. Evaluate data on the effects of lifestyle interventions and medical treatments for screen-detected prediabetes and diabetes on health outcomes over a longer follow-up period, particularly in populations that have a higher prevalence of diabetes (Topic 2).
   b. Examine how best to increase uptake of lifestyle interventions, especially among populations at highest risk for progression to diabetes and adverse health outcomes (Topic 2).
   c. Enroll racial and ethnic populations that experience a higher prevalence of prediabetes and diabetes to understand the effects of screening on health outcomes (Topic 2).

7. Screening and interventions for the prevention of dental caries in children younger than age 5 years

   a. Assess the effectiveness of oral health educational and counseling interventions for parents and caregivers/guardians of young children.

b. Enroll children from racial and ethnic populations that have historically been underrepresented (Black and Hispanic/Mexican American children) to understand the benefits and harms of risk assessment tools and preventive interventions (Topic 2).

c. Validate the accuracy and use of caries risk assessment tools for use in primary care settings and determine how referral to dental care by primary care clinicians affects caries outcomes (USPSTF, pgs. 1-3)."[6]

8. Primary Care Research Conference

Data Source Overview

Hosted by AHRQ, the two-day virtual, invite-only Primary Care Research Conference engaged primary care stakeholders to identify the highest priority research questions that will allow us to invest in research of the greatest value to the field over the coming decade. Secondary goals were to identify innovative approaches to conducting primary care research and maximize the impact of AHRQ-funded research. The conference took place from December 7-8, 2020. Discussions were detailed in a report entitled *AHRQ's 30th Anniversary Primary Care Research Conference: Proceedings.*[7]

Summary of Key Points

Stakeholders participated in seven facilitated activities that incorporated small and large group discussions. Each interactive discussion was designed to build upon the previous session, beginning with outlining significant historical and societal events that impacted primary care and a breakout group discussion. The summit participants: 1) summarized key issues facing primary care; 2) identified concepts and ideas important to the future of primary care and primary care research; 3) identified problems that were difficult to define or frame; 4) imagined innovative solutions and potential obstacles to implementation; 5) translated the previous innovative solutions into research questions addressable by AHRQ; 6) identified blind spots; and 7) built a research agenda organized into five domains: patient-centeredness, clinician and practice, system/infrastructure, community and public health, and equity and disparities.

Participants stressed the importance of health equity as a lens from which to examine all issues identified. Key concepts important to the future of primary care included workforce development (that is, a need to develop a career pipeline for primary care clinicians and other healthcare professionals amid a looming shortage of providers); electronic health data gathering, access, interoperability, and availability to patients; using technology to support relationship-centered primary care focused on whole-person health; and enabling connecting systems and primary care teams to optimize and incentivize care delivery. Participants also discussed continued advocacy for

payment structure reform, recognizing the impact of social determinants of health, and increased collaboration with Federal agencies and departments.

Shifting next to problems, participants stated the lack of a clear definition for primary care, including what should be within the purview and responsibility of the primary care provider and the difficulty in quantifying the benefits of the relational aspects of primary care to a person's health over the lifetime. They also discussed payment issues regarding underfunded reimbursement, the paucity of funding for primary care research, and the lack of bargaining power for primary care providers in both policy and payment issues.

Asked to pose solutions to the problems identified, discussion groups were asked to focus on an innovation and work through biggest obstacles to the innovation. They were then asked to list 3-5 critical solutions that contributed to the innovation success. Innovations coalesced around three broad areas: (1) the rise and enhancement of primary care by empowering primary care as a hub in the healthcare system where primary care clinicians are empowered to care for the whole person in the context of family and community, and are resourced to connect patients to other aspects of care; (2) leveraging technology and data to deliver patient-centered care that integrates clinical and social data into the electronic health record and empowers patients to have access to and engage with their own health data; and (3) achieving health equity by reforming payment to reduce health disparities, redesigning primary care workforce to match patient populations, and focusing on education, stakeholder engagement, and community wellness.

Building on the previous two discussion groups—identifying problems and crafting innovative solutions—participants organized 40 different solutions to transform into research questions for AHRQ prioritization. Some broad cross-cutting problems included inadequate data systems; insufficient human resources in primary care, including social service coordination staff and providers; patient disengagement; mistrust of the healthcare system; ongoing racial health inequities; and the role of insurance (lack of, and under-insurance). Unsurprisingly, societal problems such as food insecurity, housing, transportation, access to healthcare, and trauma were cited as additional issues impacting primary care.

Recognizing the vast array of factors that impact primary care, participants were asked to identify any missing content areas that might inform the creation of a research agenda. Content discussed did not diverge significantly from topics previously discussed. However, participants noted better use of current data sources like the National Ambulatory Medical Care Survey (NAMCS) to assess and improve primary care and more integration of qualitative and big data. They also discussed better

coordination of care, including the use of e-consults to provide more care continuity, defining and creating value for primary care, and centering primary care on what patients want and need. They cited a need for primary-care focused research and for that research to be rapid-paced, actionable, and translatable to policy and practice.

Finally, to form a research agenda, groups were given four solutions previously identified in five domains: patient-centeredness; clinicians and practices; system and infrastructure; community and public health; and equity and disparities. The teams transformed those solutions into research questions. While many are identified in the source document, those notated with an asterisk as most significant as determined by group consensus are included below.

Key questions for patient-centeredness

- Why do people seek primary care and what expectations do patients have?

Key questions for clinician and practice

- What are the short- and long-term impacts of COVID-19 on primary care? How are primary care patients and providers supported regarding the physical and emotional burden of COVID-19?
- How can we design a better model of "precision care" to address patient preferences (right care/right place/right time)?
- What is the nature of primary care-sensitive measures currently difficult to measure and how do these longitudinal measures of primary care-sensitive services perform over time?

Key questions for system and infrastructure

- What are the most effective investments that we can make in PBRN infrastructure to enable them to develop unique research methodologies that account for pragmatic and adaptive systems and to understand and improve primary care?
- What type of extension center model would be most effective in identifying and sharing best practices across primary care providers?
- How should primary care be defined and measured from a shared stakeholder perspective?
- How can primary care in the United States learn from international models of success?

Key questions for community and public health

- What value does primary care practice offer to community-based organizations for improving outcomes and minimizing burden on primary care?

- What are the data elements that a practice could use to help them understand and address health inequities within their own populations?

Overall, there are many complex questions in primary care pertaining to patient-centeredness; clinicians and practices; systems and infrastructure; community and public health; and equity and disparities. Many themes identified in the summit are long-term systemic issues and require innovative approaches to resolve.

9. Themes and AHRQ's Responses

Below we present key themes synthesized from external stakeholder input and AHRQ's associated responses to strengthen the PCORTF Strategic Framework, grouped by key characteristics. Several of the suggestions are not directly addressed in the Framework, but it is AHRQ's intention to further consider these suggestions as the Framework is implemented through its PCORTF investments and portfolio operations. We briefly describe these intentions below.

Changes made to the Strategic Framework in Response to External Stakeholder Input

Meaningful stakeholder engagement

- Stakeholders emphasized the need to engage deeply and continuously with key stakeholders throughout the research, planning and design processes of PCOR efforts. This includes participation during formative steps to develop research questions and develop metrics, but also in later stages to disseminate findings and implement projects. These comments are consistent and in alignment with our guiding principles of being "collaborative" and "stakeholder-driven." AHRQ incorporated deep and continuous stakeholder engagement as a cross-cutting strategy to achieve our goals. AHRQ's PCORTF stakeholders are broad and diverse. Stakeholders include family members and caregivers, patient advocates, community members and organizations, clinicians and support staff, healthcare provider organizations, healthcare improvement organizations, payers, policymakers, health information technology developers and vendors, researchers and academic research organizations, other funders of health services research, government and quasi-governmental partners, and others that best represent end users of healthcare improvement.
- When discussing dissemination, stakeholders commented upon who disseminates findings, the channels through which they accomplish this, and

tailoring content to specific audiences. For example, they highlighted that payment policy players such as Medicare and Medicaid will be particularly important partners in disseminating evidence-based policies for systems change. Many speakers emphasized the need to return data to communities in a format that is accessible and actionable. Speakers also noted the need to communicate effectively with policymakers. In the cross-cutting strategies, AHRQ focuses on disseminating evidence to Federal/state/local healthcare decisionmakers. AHRQ plans to disseminate findings back to other types of stakeholders (e.g., patients, communities) in formats that are accessible and actionable.

Health equity

- As opposed to depicting health equity as its own pillar or standalone priority area, stakeholders suggested that health equity is a cross-cutting strategy or guiding principle that should be applied to all areas of the framework. Additionally, stakeholders suggested that AHRQ embed health equity as an outcome within the priority areas. The Framework now indicates that health equity cuts across all areas of the Framework.
- Stakeholders emphasized the need to highlight structural factors that impact health (e.g., social determinants of health, institutional racism, implicit and explicit bias among providers in their approach to treat diverse populations) and to recognize the community and cultural context in which patients are embedded. Therefore, our PCORTF vision now reads: "Equitable whole-person care across the lifespan that acknowledges the impact of community and social context on patient health."

Trust

- The importance of trust was mentioned repeatedly and was often framed as trust by communities or groups as opposed to only individuals. AHRQ expanded the language around trust as follows: "Patient, family, provider, and community experience of care that enhances trust in the healthcare system."
- Many stakeholders stressed the importance of Shared Decision-Making (SDM) and 'co-creating meaningful care' with patients in achieving whole-person care, and felt it should be explicitly named in the framework. SDM is now explicitly called out as an additional outcome under patient, family provider, and community experience of care that enhances trust in the healthcare system: "Improved patient engagement, family engagement, shared decision-making and reported experience of care."

Cost and affordability

- Many stakeholders noticed that cost and affordability are not a focus of the Strategic Framework and suggested adding it in addition to quality of care as a patient-centered outcome. The proposed PCORTF Strategic Framework previously included cost, but not affordability, as part of our evaluation of PCORTF investments. In response to comments on its importance, AHRQ included affordability as part of the PCORTF overarching goal: "Improve health outcomes by promoting safe, <u>affordable</u>, evidence-based, integrated, coordinated, team-based, patient-centered care with a focus on underserved populations."

Training

- Stakeholders discussed the need to train future PCOR researchers and other healthcare professionals to engage meaningfully with communities, including understanding community context and learning how to disseminate research in language that is accessible to intended audiences. To meet these goals, some stakeholders recommended that community members participate in training researchers to better recognize and increase sensitivity to a community's needs. AHRQ added language to this effect in the cross-cutting strategies: "Train and support the next generation of health services researchers with a focus on team science, <u>understanding community needs</u>, and advancing health equity."

Accessible language

- Stakeholders indicated that the language used in the framework is not sufficiently accessible. They suggested that defining terms would be helpful. For example, definitions would be helpful for health equity, underserved populations, social determinants of health, whole-person care, co-design, evidence, integrated care, and digital healthcare. The PCORTF Strategic Framework now includes a glossary that defines key terms. AHRQ aims to build on AHRQ's extensive work in <u>health literacy</u>[8] using simple, clear, and accessible language throughout AHRQ's PCORTF work.

Additional Key Themes from Stakeholder Input for Further Consideration
Priority research for dissemination and implementation

- As noted above, stakeholders emphasized the need to engage deeply and continuously with key stakeholders throughout the research, planning, and design processes of PCOR efforts. This could be accomplished by prioritizing funding for the

dissemination of research that has demonstrated substantial engagement of key stakeholders. This type of prioritization is consistent with PCORI's goal in its strategic plan of re-emphasizing meaningful stakeholder engagement throughout the process of conducting PCOR.

- Stakeholders emphasized the importance of inclusivity, including collecting data from diverse populations. Setting benchmarks for funding dissemination of research that focuses on historically understudied populations would help AHRQ meet goals of improving health equity. This is consistent with ASPE's goal in its strategic plan to improve data capacity and infrastructure to support people who are medically underserved, underrepresented in biomedical research, and disproportionately affected.

- Many stakeholders emphasized the need to have rapid feedback loops between evaluation and implementation (e.g., PDSA cycles). Stakeholders also provided comments on supporting Learning Health System models or approaches that allow for a continuous feedback loop and ongoing learnings to inform how to best adapt or even pivot throughout the design, planning, implementation, and dissemination stages of healthcare improvement. AHRQ could prioritize funding for these approaches.

Governance and infrastructure

- Several stakeholders mentioned the need to have formalized structures to involve stakeholders throughout the research process, such as community advisory councils, patient advisory groups and a DEI committee to review progress on inclusivity in PCORTF efforts. As AHRQ implements the PCORTF Strategic Framework, this could be accomplished by establishing formalized structures (e.g. community advisory councils, patient advisory groups, DEI committees) through operational planning at the portfolio level and through requirements in grant or contract funding opportunities at the project level. This is consistent with PCORI's commitment to increase DEI by including individuals from historically excluded populations in its research process (e.g., as PCORI merit reviewers, peer reviewers, advisory panelists).

- Several stakeholders also noted that it is important to fund infrastructure that extends beyond project-specific needs to build sustainable engagement. This funding could, for example, support committees that evaluate the potential benefits of research to a community, capacity building for stakeholders and researchers, and continuity of academic-community relationships over time.

Metrics

- With regard to outcomes and metrics, NASEM participants commented upon the importance of collecting data to measure equitable impact. Additionally, the PCORTF SNAC provided high-level considerations for outcomes and metrics for PCORTF investments, including patient-reported outcomes and metrics that assess the extent to which systems have changed in accordance with evidence-based approaches. The subcommittee also noted that implementation science metrics could measure systems change more effectively than more common clinical and patient-focused metrics. In planning for evaluating the PCORTF portfolio and projects, AHRQ could work closely with key stakeholders to identify metrics that are meaningful to them and prioritize metrics that assess equitable impact of PCORTF investments.

Training and workforce development

- Stakeholders discussed the importance of investing in a robust pipeline of professionals who could further our mission, including primary care clinicians. In implementing and evaluating the PCORTF Strategic Framework, AHRQ could develop benchmarks for funding to increase training and workforce development in primary care. AHRQ could also combine an increased emphasis on health equity with primary care transformation and workforce development by prioritizing training of clinicians who are well versed in health equity issues and actively working in under-resourced communities. This aligns with HHS's priority to fortify and support the critical needs and emerging shortages of the primary healthcare workforce.

- As recommended by the PCORTF SNAC, AHRQ is actively expanding the scope of our training programs to recruit individuals from multiple disciplines as team members, practice facilitators, implementation scientists, and change agents in learning health systems. AHRQ's goal is to build a workforce that can advance PCOR evidence through rigorous research and implementation science. AHRQ is currently working with PCORI to co-fund increased training in this area by establishing Learning Health System Embedded Scientist Training and Research (LHS E-StaR) Centers.[9]

10. References

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