

Agency for Healthcare Research and Quality
Person-Centered Care Planning for Persons with Multiple Chronic Conditions
Summary of Learning Collaborative Session #1 – June 11, 2024

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Meeting Summary

A. Overview

The first session included an overview of the task order project by Dr. Dorr and orientation to the goals of the Learning Collaborative by Dr. De Marchis. Dr. Arlene Bierman grounded the meeting in the broader context of person-centered care planning (PCCP), including its evolution and present opportunities to expand its use and implementation. She also shared salient results from the Unmet Desire survey circulated ahead of this session. Drs. De Marchis and Miller (Task Leads) then engaged the group in discussions of their personal and professional motivations to utilize PCCP approaches, discussed and examined core components of PCCP, and solicited successful examples of these components.

B. Task Order Overview

Project Co-Director Dr. David Dorr gave an overview of the overall project vision and goals. Providing high quality, comprehensive, longitudinal, person-centered care for persons living with, or at risk for, multiple chronic conditions (MCC) is a critical challenge facing our healthcare system. Persons with MCC often navigate a complicated and fragmented healthcare system, receiving care from multiple providers across multiple health systems and practices. Fragmented care is inefficient, duplicative, costly, poorly coordinated, puts persons with MCC at increased risk for avoidable adverse events, and unduly burdens persons with MCC, families, and caregivers with the added responsibility of sharing information and coordinating care across providers. The goal of this project is to identify approaches and tools for designing, implementing, and evaluating person-centered care planning (PCCP) that will surface strategies to advance PCCP as part of routine practice. Information gathered through multi-partner engagement will provide foundational knowledge to enable AHRQ's larger long-term goal of advancing PCCP as routine practice for persons with, or at risk of developing, MCC.

C. Learning Collaborative Overview

Dr. Emilia De Marchis, Learning Collaborative Task Co-Lead, introduced the task team and gave an overview of the Learning Collaborative's goal to facilitate bi-directional learning of promising approaches to PCCP for people with, or at risk of developing, MCC and to describe feasible solutions to common

implementation barriers. Over the next eight months, the Learning Collaborative (LC) will convene five sessions to examine examples of success and failures in PCCP, generate new knowledge, and identify best practices and implementation strategies for delivering high-quality PCCP for people with MCC.

D. AHRQ Opening Remarks

Dr. Arlene Bierman thanked members for their participation and expertise, emphasized the importance of this work to AHRQ, and provided an overview of previous work that AHRQ has done to promote PCCP. There is a pressing need for health system transformation, and efforts to achieve this change must ensure alignment between policy, payment, culture, and evidence generation. Dr. Bierman highlighted the evolution of the quintuple aim. Several areas needing improvement in care for management and prevention of chronic illness include poor care coordination, lack of appropriate follow up, low patient engagement, and an environment that does not provide enough support for patients or clinicians. With a rapidly aging population and growing health care expenditures, the task to achieve AHRQ's long-term goal of advancing PCCP as an integral and routine component for persons with/at risk for MCC is more crucial than ever. Digital tools such as the MCC eCare Plan and adoption of data standards to make PCCP easier to implement in the electronic health record also play a vital role in achieving this goal. AHRQ has new methods and capacities to support agile implementation methods. To increase momentum behind this work, we need to communicate the potential for more effective use of healthcare dollars to policymakers. Improving health and wellbeing requires partnership beyond the health system, including integration of clinical care, social services, and public health.

Pre-Meeting Survey

Dr. Bierman summarized results for The Unmet Desires survey that was circulated to LC members ahead of the meeting to learn about successful models of care, barriers and facilitators to implementation, and the contribution of informal and formal collaborations to these efforts. Strategies that were identified as facilitating PCCP included involving persons with MCC and their caregiver in co-design/co-creation throughout the process; building interdisciplinary teams who also utilize person-centered approaches; emphasizing shared person-centered decision-making eliciting priorities and goals; expanding sites of care delivery (house calls, etc.); using technology to identify risks and social needs; and time and resources. PCCP barriers included inadequate time and reimbursement; need for measurable, meaningful outcomes; lack of leadership support; lack of buy-in or understanding of person-centered care in the existing culture; and lack of interoperability communicating goals across care teams. LC members described various informal strategies to enable more widespread implementation of PCCP, including simply "showing up" to help spark active conversation and collaboration, and the informal collaborations between researchers and clinicians, community organizations and patients, life care coordinators, and patient advocates and health teams. Some of the formal collaboration strategies included involving people with lived experience on research teams, engaging healthcare and public sector agencies and NGOs focused on health and social services and building community collaborations for healthcare facilities to improve hospital discharge process. Many facilitators and barriers to collaboration were identified. Examples of facilitators included: having financial alignment across service user experience and health outcomes, data access, and analyst support; age-friendly health care and public health initiatives; and trust. Examples of barriers included: lack of funding for research and for creating bridges between community organizations and healthcare organizations; siloed care settings;

and lack of clinician training in value- and preference-focused conversations. See Appendix Figure 1 for full survey results related to facilitators/barriers.

F. Learning Collaborative Member Motivations and Experiences with PCCP

LC members participated in an open discussion of their motivations and experiences with PCCP, talking about their motivations and experiences and adding insights and information in the meeting chat. Below we summarize key themes that surfaced from the discussion.

Desire to center patients and improve their well-being.

LC members shared their personal and professional motivations to help patients by meeting people where they are, honoring their values and goals to align care with what matters most to patients. Supporting autonomy and dignity of people who have MCC while also supporting care partners and preparing them to be decision makers are key goals.

Focus on quality and regulatory requirements.

LC participants noted that a shared understanding of treatment goals can feel stymied by regulations that push for efficiency even though patient-centered care plans save time overall as patients' wishes are known and recorded. Participants also noted that quality measures don't align with what matters most to individuals.

Connecting the Learning Collaborative to the day to day.

Meeting participants want to know how conversations on and motivations for PCCP can connect to the day-to-day issues that must be overcome to help practitioners understand what they can do today to make a patient's tomorrow the best that it can be.

Training

Meeting attendees expressed the need for training on PCCP for clinicians, health care support staff, community health workers, as well as patients and their care partners. LC participants want to learn more about how to train health care staff and clinicians so that PCCP is integral to the care they provide, as well as how to educate and empower patients and care partners to expect and ask for PCCP.

"People feel homeless for medical homes"
- Neeraj Arora, LC participant

G. PCCP Components for People with or at risk of MCC

LC members participated in a whiteboard activity where they were asked to identify components that are needed for successful implementation of PCCP. First the seven core components of PCCP were described:

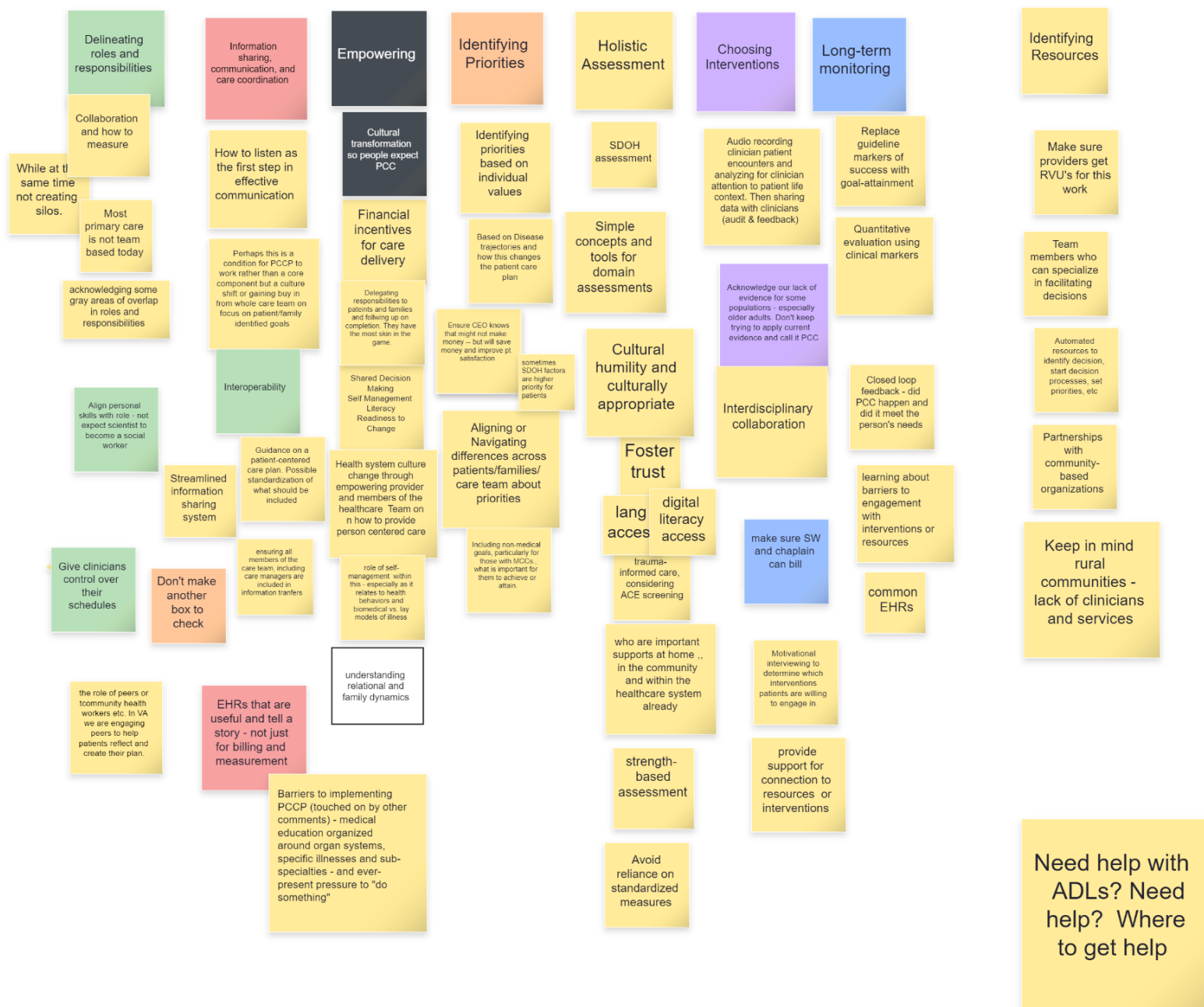
1. **Holistic assessment** including physical, mental, and behavioral health conditions; functional status; personal preferences, values, priorities, and goals; socioeconomic, environmental, occupational, and cultural factors; and life roles and responsibilities
2. **Identifying priorities** including problems, needs, and goals
3. **Choosing interventions** for prioritized problem areas, needs, and goals, including medical, behavioral, and social interventions and supports and minimize harmful interactions between treatments
4. **Delineating roles and responsibilities** of each care team member, including the person/family/caregivers
5. **Long-term monitoring** + follow-up across health systems/providers
6. **Information sharing, communication, and care coordination** across the entire care team, including the person/family/caregiver
7. **Empowering** persons, families, and caregivers to engage in self-management.

Then, meeting participants were asked to add sticky notes to a virtual whiteboard with the 7 components listed at the top. There was space to add examples of successful elements of PCCP for each component and to add additional components, if desired. Figure 1 illustrates the input provided. LC members added cultural humility, culturally appropriate care, and patient spirituality and beliefs. Participants also acknowledged two overarching issues: the lack of system-level commitment to PCCP outside the patient/provider dyad and a dearth of meaningful measures for PCCP that address the core components.

In preparation for LC session #2, we will migrate the whiteboard findings into a matrix, adding any additional responses from members who could not attend. We will then remove redundant suggestions and present the matrix for further LC feedback.

Figure 1. Whiteboard activity

What are the components you need for successful implementation of PCCP?



H. PCCP Priority Goals and Obstacles

Dr. Lyndsey Miller led participants through a poll of their PCCP priority goals, which were then discussed further. Poll options for priority goals were selected from aggregated responses of an AHRQ request for information on PCCP. The top priority from the list was meeting patients where they are (74%), followed by addressing social needs (66%), shared decision making (57%) and goal-concordant care (57%). New priority goals suggested by Learning Collaborative members included trust, standardized PCCP measures to drive quality, and avoiding creation of another box to check. Please see Appendix Figure 2 for the full poll results.

What are your priority PCCP goals?

1. Goal-concordant care
2. Shared decision making
3. Meeting patients where they are at
4. Addressing social needs
5. Addressing language/cultural barriers
6. Health systems culture change
7. Home/community-based care and services
8. Additional Goals (specific to your area of work)

Next, participants completed a quick poll voting on the main obstacles to providing PCCP. Workforce training/retention (72%) and reimbursement challenges (72%) were most frequently selected, followed closely by short visit times (68%). Additional discussion emphasized that time was the #1 obstacle, which is driven by payment models, health system organizations, and valuations of care. A fixed mindset/resistance to change was also noted as another key obstacle. Please see Appendix Figure 3 for the full poll results.

What are the main obstacles in the health care system working against PCCP?

1. Short clinic visits
2. Patient and family social risk factors
3. Language and cultural barriers
4. Lack of evidence for PCCP for diverse populations
5. Challenges around reimbursement
6. Workforce training and retention
7. Additional obstacles (specific to your work)

I. Ranking Facilitators & Obstacles

Participants moved into breakout groups to rank the priority PCCP goals and obstacles from the previous exercise. All four of the breakout groups ranked health system culture change as their highest priority, with three groups ranking this goal as their highest priority and one group ranking this goal as their second highest priority. Shared decision-making, meeting patients where they are at, and trust were also in the top three goals of each group. Groups had differing perspectives on obstacles in the healthcare system working against PCCP. The greatest obstacle for each group varied from challenges around reimbursement, provider buy-in, and short clinic visits. Short clinic visits were highlighted as a high-

ranking common obstacle across all groups. Other main obstacles noted by groups included lack of evidence for PCCP for diverse populations, language and cultural barriers (reframed in one group as lack of resources to adequately accommodate language and cultural differences), and lack of commitment/leadership to promote PCCP culture. During the full group report out, several groups brought up the need for meaningful, standardized measurements for PCCP. Measurement was mentioned as an important way to drive clinician and health system buy-in, which helps foster a culture that promotes and prioritizes PCCP. Participants also noted the interconnectedness and interdependence of both the goals and obstacles, including having adequate resources/time and reimbursement, and the ability to achieve provider buy-in and need for a culture shift in the practice of care. Appendix Figures 4 and 5 provide more detailed information on the results of the ranking activity in the breakout rooms.

J. Closing/Feedback

At the end of the session, the project team requested feedback and a call for future session topics. Participants expressed a desire to continue having breakout groups in the future. Some participants found it difficult to keep up simultaneously with the chat and speakers. Future session suggestions included: successful PCCP models, a presentation of the GUIDE model by Learning Collaborative members Drs. Boustani, Reuben and Borson, measures of healthcare system culture change and patient satisfaction, and PCCP trainings for clinicians. There was also a request to set the remaining Learning Collaborative meeting schedule.

K. Shared Resources

Fulmer T, Patel P, Levy N, Mate K, Berman A, Pelton L, Beard J, Kalache A, Auerbach J. **Moving Toward a Global Age-Friendly Ecosystem**. J Am Geriatr Soc. 2020 Sep;68(9):1936-1940. doi: 10.1111/jgs.16675. Epub 2020 Jul 23. PMID: 32700767.

Trager Institute <https://www.tragerinstitute.org/>

CAPABLE Program <https://nursing.jhu.edu/faculty-research/research/projects/capable/>


Funding Opportunity **Special Emphasis Notice: AHRQ Announces Interest in Health Services Research to Improve Care Delivery, Access, Quality, Equity, and Health Outcomes for Older Adults**
<https://grants.nih.gov/grants/guide/notice-files/NOT-HS-24-013.html>

Report to Congress - Aging in the United States: A Strategic Framework for a National Plan on Aging
<https://acl.gov/sites/default/files/ICC-Aging/StrategicFramework-NationalPlanOnAging-2024.pdf>

L. Appendix

Figure 1. Unmet Desire Survey: Interventions, Collaborations, and Facilitators and Barriers (Session 1 Slides 22-25)

Unmet Desire Survey Interventions



What has worked


- ▶ Involving patients/caregiver in co-design/co-creation
- ▶ Interdisciplinary teams
- ▶ Open, transparent, and honest communication
- ▶ Listening to what matters most to the patient and prioritizing that in visits
- ▶ Extended time for primary care visits
- ▶ House calls to home-limited, high-risk patients
- ▶ Use of Whole Health Coaches
- ▶ Emphasizing shared person-centered decision-making eliciting priorities and goals.
- ▶ Identify risks across multiple domains.
- ▶ Use of EHR data to risk stratify
- ▶ Assessing health-related social-needs
- ▶ Refer to clinicians who also take a patient-centered approach.
- ▶ Create overarching measurable outcome goals, but also design interventions to be individualized
- ▶ Teaching interdisciplinary colleagues about the importance of spiritual care/meaning
- ▶ Working at the system level AND System support
- ▶ Community building
- ▶ Money

Barriers

- ▶ Insufficient time
- ▶ Inadequate reimbursement
- ▶ Discordant values between caregivers and patients
- ▶ Communicating goals across teams and providers
- ▶ Team buy-in
- ▶ Getting providers to understand what we mean by PCC
- ▶ Integrating research findings into clinical workflows
- ▶ Siloed clinical service lines
- ▶ Lack of interoperability across EHRS
- ▶ EHRs don't support care-planning
- ▶ Lack of leadership support
- ▶ Need for measurable, meaningful outcomes
- ▶ Over-focus on easily measured outcomes for specific conditions/diseasesLack of insurance, resources
- ▶ Lack of evidence-based guidelines for quality end-of-life care
- ▶ Unless it 'pays', it's a non-starter
- ▶ Money-financial competing factors

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Unmet Desire Survey Collaborations



Informal

- ▶ The mere **presence/showing up helps sparks active conversation and collaboration.**
- ▶ Researchers and clinicians
- ▶ PCP and hospital teams
- ▶ Between multidisciplinary team members
- ▶ Community organizations and patients
- ▶ Across home based primary care staff (clinicians, pharmacist, care manager, home health agency and hospice)
- ▶ Patient-Priorities Care model and Age Friendly Health Systems
- ▶ Life care coordinators (Geri care managers) with family members (caregivers) and patients.
- ▶ Patient advocates and health teams
- ▶ Peer support
- ▶ Discussions at conferences

Formal

- ▶ Including people with lived experience on research teams
- ▶ Healthcare and public sector agencies and NGOs focused on health and social services.
- ▶ Researchers Behavioral Health and other Chronic Conditions
- ▶ Implementation of Patient-Priority Care
- ▶ CBO and IT for referrals
- ▶ Community collaborations for healthcare facilities to improve hospital discharge process.
- ▶ CDC and CMS for improving care coordination.
- ▶ Serving on Board of community-based organization with of healthcare organization
- ▶ Designers during development of intervention

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Unmet Desire Survey Collaborations -Facilitators



- **Financial alignment** with service user experience and health outcomes, data access, and analyst support
- **Age-friendly health care and age-friendly public health initiatives** create opportunities and provide training to support collaborations among healthcare professionals and organizations.
- **Coalitions with aligned vision, mission, values, goals,** and willingness to pool resources.
- **Funding** from ACL allowed a community-based organization (CBO) to implement projects with guidance and support, contributing to improved care delivery and outcomes.
- **Trust**

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Unmet Desire Survey Collaborations-Barriers



- **Lack of funding for research and creating bridges** between community organizations and healthcare organizations
- **Lack of knowledge of what works** to unify (de-fragment) healthcare system.
- **Siloed nature of care settings**
- **Clinicians not getting training** in value- and preference-focused conversations.
- How **exhausted and overworked** everyone is.

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Figure 2. Results from priority PCCP goals poll

1. What are your priority PCCP goals? (Multiple choice)

(35/35) 100% answered

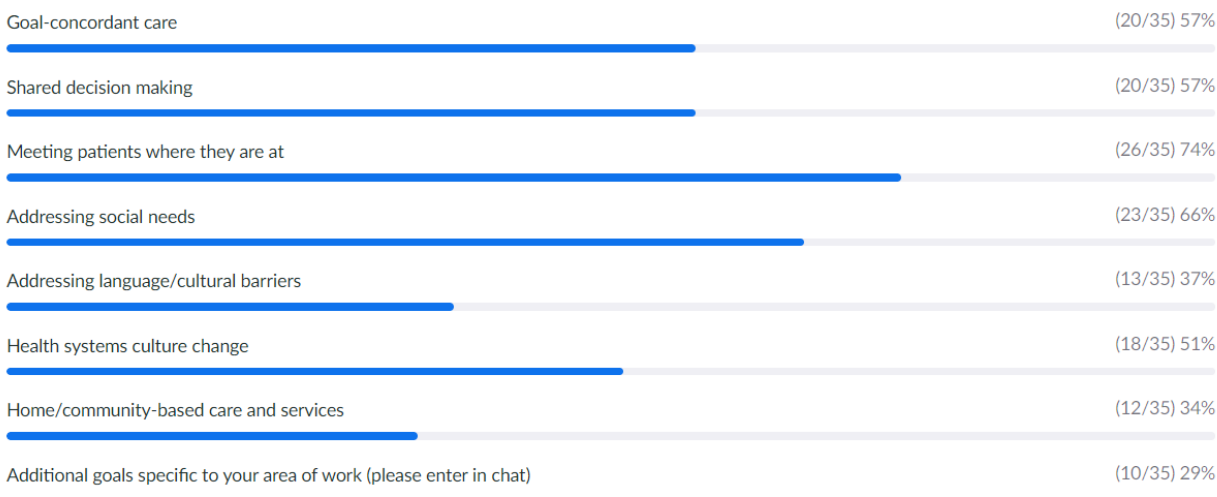


Figure 3. Results from main obstacles working against PCCP poll.

1. What are the main obstacles in the health care system working against PCCP? (Multiple choice)

(25/25) 100% answered

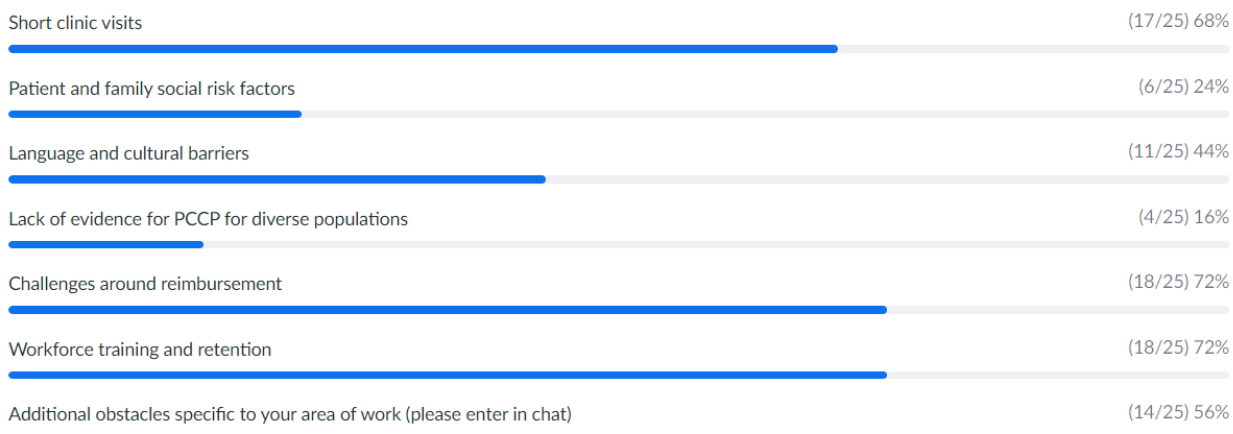


Figure 4. Example from priority PCCP goal ranking activity in breakout group.

Rank your group's priority PCCP goals:	Rank (votes)	Why did you rank this way?
Goal-concordant care - includes PCCP goals	3 (2 votes)	
Shared decision making - includes who makes decisions	2 (3 votes)	MCCP - polypharmacy issue
Meeting patients where they are at	3 (2 votes)	
Addressing social needs	3 (2 votes)	
Addressing language/cultural barriers	3 (2 votes)	
Health systems culture change	1 (4 votes)	Clinical training and loan forgiveness to eliminate need to go into particular specialties
Home/community-based care and services	7 (1 vote)	
Aligning policy		
Facilitate coordination of care	7 (1 vote)	
Culture change in clinical training: chronic disease and PCCP	7 (1 vote)	
Patient-centered care in spiritual care education		
Clinician attention to patient life context		
Health care literacy, disparity, and cognitive impairment		
Clinician/health care team education: culture/mindshift change	7 (1 vote)	lack of end-of-life care clinical guidelines
Patient/family education, empowerment		
Partnership model - continuity of care	7 (1 vote)	
Trust	3 (2 votes)	Important to trust that clinician will have patient's back

Figure 5. Example from obstacle ranking activity in a breakout group.

Rank your group's PCCP obstacles from 1 to 7:	Rank	Comments/Justification
Short clinic visits		
Patient and family social risk factors		
Language and cultural barriers		
Lack of evidence for PCCP for diverse populations		
Challenges around reimbursement		Payment systems drive interest and buy-in
Workforce training and retention		
Provider buy-in	1	
Lack of commitment / leadership to promote PCCP culture	2	Commitment and culture will promote meaningful measurement, address visit length, think whole person; some do better at this
Clinician/health care team education: culture/mindshift change	4	
Patient/family education		
Improve health care access		
Technology	5	
Health care priorities		
Meaningful measurement	3	Measurement drives clinician / system buy-in