November 15, 2022

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

Dear Dr. Valdez:

AcademyHealth welcomes the opportunity to provide input to the Agency for Healthcare Research and Quality (AHRQ) on the current state of comprehensive, longitudinal, person-centered care planning for people at risk for or living with Multiple Chronic Conditions (MCC) across settings of care. MCC are defined by AHRQ as the co-occurrence of two or more chronic physical or behavioral health conditions (including mental health and/or substance use disorders). This type of planning is essential to developing and implementing models of care that deliver high-quality, equitable, and accessible care for people who are at risk of MCC or are living with MCC. Both development and implementation require active and meaningful partnerships with diverse stakeholders, importantly patients, and the ability to implement the most recent and best evidence in a timely manner.

When AHRQ was authorized in the Healthcare Research and Quality Act (Public Law 106-129), it cited as a priority population for research, evaluations, and demonstration projects "*individuals with special health care needs, including individuals with disabilities and individuals who need chronic care or end-of-life health care*." This highlighted the integral relationship between AHRQ research and patients with MCC. According to the CDC, 26 percent, or 61 million adults, in the United States have some type of disability and has unique healthcare access needs.

What are your general thoughts on how AHRQ can support people with Multiple Chronic Conditions?

AHRQ and health services research (HSR) are both uniquely qualified for funding and conducting the type of whole-person research that disproportionately supports diverse MCC populations and persons with disabilities (PWD). AHRQ should continue to focus on supporting this type of research. AHRQ could support studies that aim to identify specific care coordination methods that work best for people with MCC and determine what distinct patient characteristics, including family, home, and community conditions, enhances patient-centered care for this population. In particular, attention to the social determinants of health will be critical. For example, AHRQ should look for, or develop opportunities to comparatively study health in two communities that have tried to address issues at the intersection of SDOH and MCC. This is because developing specific approaches for how health systems could address these domains could guide providers and researchers in sharing best practice methods and techniques in primary care. A learning health system (LHS) is a framework that places the patient at the center of his or her care. Additional AHRQ research is needed on how LHSs can effectively improve care and outcomes for diverse MCC and PWD populations to promote progress on equity, continuous learning, data and analytics generation, and stakeholder engagement to improve care practices.

What terms, strategies, and models of care are used to describe and deliver care planning for the whole person (not just for individual health conditions) that records: (1) roles and tasks among care team members, including the individual, their family and caregivers; (2) plans for coordinating

care within and across organizations and settings; (3) strategies for supporting and empowering patients to manage their own health; (4) plans for engaging in shared decision making?

It is of utmost importance to consider disability-related access/accommodation needs when engaging in care, given the prevalence of PWDs in the U.S. and the co-occurrence of disability with MCCs. In order to better inform patients, engage them, and better enable them to navigate their care, they must first have their accommodation needs met. Disability status and accommodation needs are still not systematically coded in the electronic health record (EHR), creating barriers to accommodation provision and care coordination, even though development of that taxonomy is [underway] with the Office of the National Coordinator for Health Information Technology (ONC). Therefore, one model of care that will improve patient-centered care for people with MCCs is recording disability-related accommodation needs in their medical record. AHRQ can work with other federal agencies (e.g. the Office of the National Coordinator and the Centers for Medicare and Medicaid Services) to measure the impact of this work.

Integrated primary care delivery models such as the Patient-Centered Medical Home (PCMH) is a team-based, coordinated care approach that can improve patient outcomes, expand the roles of non-physician health professionals, and promote effective use of information technology. The PCMH model has been shown to effectively manage chronic disease, boost patient and provider satisfaction, and enhance the quality of care. AHRQ can build on existing evidence to further develop and test models across different populations and contexts (e.g. rural settings) that include assessing and addressing social risk factors, the patient's medical needs, community-based resources, and how payment systems can support high value, equitable care delivery approaches.

What key components are necessary to fully deliver on the promise of person-centered care planning?

Highly integrated systems may have the tools to make progress on high value, equitable person-centered care, but there is need to test and develop effective and sustainable interventions for less-resourced systems. Historically, these innovations have started or were imposed on highly resourced systems with intentions to trickle down; however prioritizing healthcare providers in low income and historically excluded communities, including federally qualified health centers, could be more effective in reducing and eliminating disparities. There is need for changes to the payment structure, the development of better team care, and acknowledgment of the care planning process, not just the care plan itself. One potential lever for AHRQ to consider is the use of a request for funding proposals for teams to determine best practices for designing and implementing innovations related to care for patients with MCC, with an emphasis on including smaller, less resourced systems, such as federally qualified health centers.

One approach to delivering person-centered care could include a process or program for health workers, including community health workers, to provide care to those with MCC and PWD populations where they live. Care management planning, which includes documenting the patient's preferences and other information for developing care plan needs are collected at the patient's residence rather than at the doctor's office by deploying community health workers. Additional research is needed on using FQHCs to address some of these innovations or models of care.

Who are the thought leaders in this area and/or where would leaders go to seek information about how to begin this work?

AcademyHealth has numerous active members focusing on MCC and PWD populations and stand ready to assist AHRQ in connecting with them. For example, we have an interest group on disability research as well as prior and current theme leaders and reviewers for the Annual Research Meeting themes on High Cost, High Need Populations and Disability, Aging and End of Life Care.

What are examples of innovative models of care, approaches, promising strategies and solutions that could support clinicians and practices in routinely engaging in comprehensive, longitudinal, person-centered care planning to improve the care of people at risk for or living with MCC?

AcademyHealth has a robust network of engagement across a range of delivery system organizations actively engaging in innovative models of care. We are eager to assist AHRQ in identifying these.

What are best practices for designing, implementing, and evaluating person-centered care planning for people at risk for or living with MCC? What implementation challenges are clinicians and systems likely to face?

Social drivers of health (SDOH) as well as systems of power between patients and health systems have both systemic and individualistic implications for the health outcomes of all patients, but especially among people with MCCs, which may lead to worsened conditions. Overlooking these structural conditions in favor of classical individual-responsibility views, may lead to unnecessarily worse health outcomes. People who live in areas prone to more significant noise pollution, poor housing quality, poor air or water quality, and exposure to other adverse structural conditions are at higher risk for MCCs.

Major implementation challenges today include staffing, burnout, and fragile health systems that are still suffering the financial impact of the pandemic. Healthcare systems throughout the U.S. suffer from staffing challenges that were present before and made worse during the COVID-19 pandemic. Healthcare worker burnout is now a crisis in healthcare and concerted attention is needed as called for in the recent Surgeon General's advisory. The evidence base for the effectiveness of individual clinician focused interventions has grown and shown small to moderate effectiveness, however much more research is needed on the effectiveness of system wide interventions. In addition, several recent systematic reviews have pointed out the poor quality of the existing evidence base. What we do know is that care for MCC and PWD populations is more complex and demanding, making it even more critical to reduce clinician burnout. AHRQ could play a significant and timely role in improving this evidence base. At the same time, continuing provider and staff burden and burnout, paired with these staffing challenges, are causing patient safety issues, breakdowns in quality of care, and other systemic issues which further impact multiply marginalized populations like PWDs/people with MCCs.

What are suggested strategies for effective implementation of person-centered care planning at multiple levels (e.g., policy, system, practice, clinical team, people with MCC)?

Studying the consequences of disability and/or MCCs in all health services research, including comparative effectiveness research, is critical. These analyses need to additional address biases that contribute to disparities and the potential devaluation of some lives over others. These groups comprise a sizeable portion of the U.S. population, even among pediatric populations; however, they are often excluded from research studies. AHRQ has the unique authority and focus to lead the health research field in including MCCs in their funded research studies. For example, the use of ICD-10-CM Z-codes (e.g., psychosocial risk and socioeconomic determinate-related codes) in data collection to systematically collect social circumstances influencing population health can help researchers and practitioners capture SDOH at the individual, community, health system, and policy levels. We need a more helpful depiction of social determinants that is not simplified too much to one factor – for that more robust sets of data to use are necessary. We also need better tools to collect data at the point of care; then develop data sets that require more clinician input rather than solely from EHR software developers. These are areas that AHRQ can have significant influences.

What quality of care measurements (e.g., metrics, indicators) exist or are emerging for assessing process, implementation, and outcomes associated with person-centered care planning?

AHRQ has the opportunity to build on their pioneering role in the development of patient experience of care reporting with the CAHPS family of surveys. Further expanding them to capture the many dimensions of care for MCC and PWD populations would be important. In addition, there is heterogeneity in defining and describing patient-centered quality indicators (PC-QIs). Patient-reported measures collected from people with disabilities and people with MCC could be used to assess patient-centered outcomes and patient preferences accurately. There are several domains to evaluate the process of person-centered care planning, such as respectful and compassionate care, cultivating communication, engaging patients in managing their care, integration of care, and access to care. A critical factor for successfully implementing person-centered care (PCC) is whether structures are in place to develop a PCC culture and a supportive workforce committed to PCC.

To conclude, we appreciate the work and focus that AHRQ brings to the MCC population and look forward to working with the agency closely on developing strategies to maximize the impact of AHRQ funded research programs. For further comment, clarification, or inquiry, please email Josh Caplan at Josh.Caplan@AcademyHealth.org.