

**Proceedings from  
AHRQ Summit on Transforming Care for  
People Living with Multiple Chronic Conditions**

November 17-18, 2020

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## Introduction and Background

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### **The Problem: Definition, Scope, Burden**

One of the most daunting challenges confronting the healthcare system is how to prevent and manage multiple chronic conditions (MCC) effectively and efficiently. MCC are commonly defined as the co-occurrence of two or more chronic physical or mental health conditions. Some use the term multimorbidity as synonymous with MCC, while others define MCC as including additional factors that contribute to the burden of illness, including disease severity, functional impairments and disabilities, syndromes such as frailty, and sometimes social factors such as homelessness.

Regardless of definition, MCC are common, costly, and place a high burden on individuals, their caregivers, clinicians, healthcare teams, and health systems alike. Although prevalence varies with definition, MCC is the most common chronic condition seen in clinical practice. One in three American adults, four in five Medicare beneficiaries, and a growing number of children have MCC. People living with MCC account for a disproportionate share of healthcare utilization and costs, 64% of all clinician visits, 70% of all in-patient stays, 83% of all prescriptions, 71% of all healthcare spending, and 93% of Medicare spending. Almost half have functional impairments. Nearly all readmissions among Medicare beneficiaries occur among those with MCC. The prevalence of MCC will grow with our aging population. The ongoing COVID-19 crisis has further illuminated the disproportionate burdens and challenges borne by racial and ethnic minorities and low-income populations who experience a higher burden of MCC and develop them at earlier ages. There is now a broad recognition of the importance of addressing social determinants for all patient populations but perhaps most especially for people living with MCC.

The need to improve the care of people living with MCC has been recognized nationally and internationally. In the U.S., much attention has been given to how our fragmented, disease-focused healthcare system is ill-suited for serving the needs of this growing population. The increasingly urgent need to identify research priorities, and novel research methods, on patient-centered, system-based solutions for meeting the needs of people living with MCC (PLWMCC) was the motivation for AHRQ's 2020 MCC Summit.

### **AHRQ's Role in Transforming Care for People Living with MCC (PLWMCC)**

The mission of the Agency for Healthcare Research and Quality (AHRQ) is to produce evidence to make healthcare safer, higher quality, more accessible, equitable, and affordable, and to work within the U.S. Department of Health and Human Services and with other partners to make sure that the evidence is understood and used. More specifically, AHRQ is the only federal agency whose primary mission is to

develop and disseminate evidence on strategies for improving the patient-centeredness, efficiency, and effectiveness of *healthcare delivery*. Since the challenges facing PLWMCC are so fundamentally grounded in poorly-designed processes and structures of care delivery, pursuit of solutions to these challenges has long been a significant focal area for AHRQ. AHRQ has had a longstanding interest and made myriad investments in improving care delivery for PLWMCC; as further described [here](#).

In 2019, AHRQ articulated the following vision as to guide the development of a comprehensive plan for addressing the needs of PLWMCC: *a sustainable healthcare system that delivers high-value, coordinated, integrated patient-centered care, based in primary care, that will optimize individual and population health by preventing and effectively managing multiple chronic conditions*. In support of this goal, the Agency launched a multi-step process of engaging stakeholders (described further below) to help frame an agenda for future AHRQ-funded research that could meaningfully address the burgeoning needs of the growing numbers living with or at risk of developing MCC. The subsequent arrival of the COVID-19 pandemic served to further emphasize the urgency of AHRQ's goal, as the numbers and needs of PLWMCC continued to grow and the disproportionate burdens and challenges borne by racial and ethnic minorities and low-income populations came into even greater focus. The *2020 AHRQ Summit on Transforming Care for PLWMCC* was the culmination of AHRQ's 18-month stakeholder engagement efforts.

### **The 2020 AHRQ Summit on Transforming Care for PLWMCC: Planning and Structure**

AHRQ has a long history of convening key stakeholders -- including patient advocates, clinicians, researchers, health system leaders, community organizations, professional societies/organizations, policymakers, foundations, and federal partners --- to inform and shape its efforts and investments. Engagement of these diverse stakeholders is especially critical for addressing complex challenges requiring collaborative, integrated, cross-disciplinary, multi-sector solutions, like the challenges of preventing and managing care for PLWMCC. Thus, in early 2019 AHRQ launched a series of stakeholder engagement activities to support the Agency in developing a research agenda to guide future MCC-related investments. Activities included key informant interviews, open forums, and panel discussions at professional society meetings designed to elicit comprehensive and diverse perspectives from clinicians, patients, health system leaders, academia, and philanthropies about the most pressing challenges in improving MCC care and research needed to address these challenges.

Through this process AHRQ identified three broad domains that collectively captured the most commonly cited areas of needed MCC research and commissioned three evidence reviews to assess the

state of the evidence in the specified domains and expose key knowledge gaps that remain unaddressed. The domains were:

1. *Patient and Family Engagement Among Persons with Multiple Chronic Conditions*
2. *Models of High Value Care for People with Multiple Chronic Conditions*
3. *Health IT Solutions for Persons, Practice, and System-Level Challenges Associated with Caring for People with Multiple Chronic Conditions.*

The evidence reviews provided context and framing for two stakeholder meetings at which input was sought in an iterative process from successively larger and more diverse groups of stakeholders representing expected beneficiaries, users, and producers of future AHRQ MCC research.

The first meeting was a May 2020 Planning Meeting at which 40 invited participants (clinicians, patients and caregivers, researchers, healthcare system and policy experts, and HIT professionals) were asked to provide feedback on outlines of the planned evidence reviews and to identify any key topics, issues or themes not likely to be sufficiently covered in the three papers for inclusion in the forthcoming Summit agenda. Participants were also asked to provide initial feedback to the three pairs of authors on their planned approaches and to recommend additional participants for the Summit. Participants identified health equity as an important cross-cutting theme. They emphasized that future research will need to respond to the sizable impact of the COVID-19 pandemic on people living with MCC, their caregivers, clinicians, and the care-delivery system.

At the subsequent November 19-20, 2020 *AHRQ Summit on Transforming Care for PLWMCC*, an even larger group of participants met to advise AHRQ on key areas of research for transforming care for PLMCC. The Summit combined plenary sessions to provide background and articulate the challenge, with a series of small-group working sessions designed to yield a research agenda for AHRQ with a high likelihood of sustained impact on addressing known challenges in the prevention and care for PLWMCC.

### **Summit Participants**

More than 100 attendees represented diverse perspectives including experts in research and/or clinical care for PLWMCC, patients, caregivers, policymakers, and funders as well as representatives from other federal agencies.

#### **Available Materials:**

- [Participant Bios](#)

## Meeting Summary

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### Plenary Sessions: Overview

The Summit kicked off with five plenary sessions designed to provide a shared understanding of the purpose of the Summit and of the challenges and opportunities for improving care for PLWMCC. AHRQ leadership articulated the Agency's goals for the Summit and AHRQ's perspectives on the challenge of transforming care for PLWMCC. This was followed by presentations of the lived, real-world perspectives of a patient and a health system leader. The authors of the three evidence reviews then provided a preview of their findings of what is known about approaches for addressing known challenges and remaining research needs, and an expert on research methods provided a high-level overview of innovative research methods to address these needs.

Brief summaries of each of these sessions follow below with links to presenters' videos and slides where available.

**Plenary Session 1: Welcome:** In their opening statements, the Director of AHRQ, and Arlene Bierman, MD, MS, Director of AHRQ's Center for Evidence and Practice Improvement (CEPI), identified transforming care for PLWMCC as a top priority for AHRQ. They set forth the purpose of the MCC Summit as helping AHRQ develop a research agenda informed by wide-ranging perspectives that will help advance toward AHRQ's vision of *a sustainable healthcare system that delivers high-value coordinated, integrated patient-centered care based in primary care optimizing individual and population health by preventing and effectively managing MCC*. They underscored that there is great potential for more effective use of healthcare dollars while improving quality of life and population by realizing this vision.

Dr. Bierman addressed the definition, scope, and burdens of effectively meeting the needs of PLWMCC and emphasized AHRQ's long history of reaching out to stakeholders to support internal strategic planning activities. She noted that several factors have created a window of opportunity for meaningfully addressing the needs of individuals with MCC, starting with the growing recognition—as a result of the COVID-19 crisis—of the disproportionate burden of MCC on individuals and the healthcare system. A study early in the crisis found that 88% of people hospitalized for COVID-19 have MCC. Racial and ethnic minorities, and low-income people have been disproportionately impacted by COVID-19. The aging of the population and rising income inequality will contribute to the growing burden of MCC. There is increased recognition of the importance of addressing the social determinants for all patient populations, which is essential for preventing MCC and addressing the needs of PLWMCC. The success of

payment incentives and penalties encouraging systems and providers to provide more high-value, person-centered care is dependent on redesigning the system to meet the needs of PLWMCC. New methods and capacities including new digital health tools and applications and new scientific methods to study healthcare improvement interventions increase likelihood of success.

Dr. Bierman instructed Summit participants to keep the full scope of the challenges and potential solutions in mind in their discussions, including considering the needs and challenges not only of those living with MCC, but also those at rising risk of developing MCC in the future; considering solutions from beyond the walls of the Medical Home by better leveraging resources from the broader medical neighborhood, linkages with community services and cross-sectoral collaboration; and ensuring that issues of health equity and improved care for traditionally underserved populations remain a central focus of all discussions. Finally, she underscored that innovative research methods will be needed to identify sustainable solutions to the challenges that have been identified.

#### **Available Materials for Plenary Session 1:**

- [Dr. Bierman slides](#)

***Plenary Session 2: Patient Perspective: A Conversation About Living With MCC:*** Prior to the Summit, participants had the opportunity to listen to a video presentation by Richard Knight, MBA, describing his decades-long experience navigating the healthcare system for treatment of his multiple chronic conditions. During the Summit, Mr. Knight shared additional insights informed by experience as a kidney transplant recipient, as well as his professional experience on Capitol Hill where he served in various roles including communications and policy, as well by his advocacy work as President of the Board of Directors of the American Association of Kidney Patients.

Mr. Knight framed the challenges of addressing the needs of PLWMCC as ones of leadership, strategy, and management, rather than science. He observed that our highly siloed healthcare system is poorly designed for providing collaborative, team-based care necessary for creating the individualized, whole person approaches that are needed, and he stressed the importance of including PLWMCC as equal partners in that collaboration. He cited needed changes in education (away from optimizing care for a single disease) and reimbursement policies (away from fee-for-service) as essential for movement toward the comprehensive approach that is required, and noted both the opportunities and challenges associated with technology-based solutions to problems of communication, information-sharing, and care coordination. Mr. Knight urged Summit participants to seek and prioritize patient-driven solutions

for transforming care and reminded them to focus their understanding on the challenges of seeking effective care for MCC not as theoretical constructs, but rather as what PLWMCC experience every day.

***Plenary Session 3 (Keynote): Opportunities and Challenges for Transforming Care for People Living***

***With MCC:*** Prior to the Summit, participants had the opportunity to view a video and slide presentation by Keynote Speaker, Lisa Rubenstein, MD, MSPH, FACP, followed by a facilitated discussion at the Summit, all of which focused on the need to improve research to develop and integrate system-level interventions to achieve population impact.

Dr. Rubenstein highlighted a variety of challenges to designing and studying effective interventions for individuals living with MCC, many of whom constitute a high need and high-cost population whose challenges cannot be merely characterized as the simple sum of their individual diagnoses. These challenges include how to define the target population for intervention; how to best provide their care in primary care systems not equipped to meet their needs nor fully integrated into the larger systems of care; shortcomings of research to date on system-level interventions, and the absence of widely accepted measures for assessing “what it means to deliver better care to individuals living with MCC.” Looking ahead, she describes a need for studies that better evaluate interventions using rigorous methods, using relevant measures of patient-centered quality of care and costs with sufficient follow-up to assess population impacts. Interventions must be cost-effective, readily adopted within real-world healthcare settings, and accessible to the entire target patient population. Particular attention was raised to the importance of continuity of care, scalability, patient-and caretaker-centeredness, understanding goals and preferences, using coordinated care models to link with key resources, and use of information technology to better coordinate processes and enhance understanding of what matters to each person. She noted several underappreciated aspects of doing research in this patient population: the importance of gaining the trust of patients and caregivers in investing in these complex interventions; the need for multi-dimensional functional assessments (e.g., social, role, physical, mental); agenda setting and care planning; and care team health and functioning.

**Available Materials for Plenary Session 3:**

- [Rubenstein Pre-meeting Keynote Video](#)
- [Rubenstein Slides](#)

***Plenary Session 4: What We Know and Where Are the Gaps: Authors’ Insights from Their Research:*** In advance of the Summit, AHRQ commissioned three evidence reviews examining current MCC research through three lenses: (1) high value models of care; (2) person and family engagement; and (3) uses of



health information technology. Background on all three reviews was provided to participants in videos and presentations. These three papers, informed by the Summit, were subsequently accepted for publication in a special journal supplement of *Health Services Research (HSR)* that will be published in October 2021 on *The Science of Care for People with Multiple Chronic Conditions*. In videos shared prior to the Summit, and during their Summit presentations, the authors shared the following reflections from their forthcoming papers:

- In *Models of Care for Individuals with MCC*, authors Elizabeth Bayliss MD, MSPH, and Lucy Savitz, PhD, reviewed published delivery paradigms and conducted a series of semi-structured interviews with health system and clinical experts in addition to reviewing the literature. They reported that they did not identify any clear, scalable, evidence-based models for high-value care (HVC) in MCC but did identify promising attributes and concepts from the literature on comparable complex care implementations, including reliance on team-based strategies. Most frequently cited in the interviews were: the importance of taking a patient-centered approach, with inclusion of in-home care, remote patient monitoring, and virtual care (all possibly accelerated by the 2020 COVID-19 pandemic). Other important concepts included: addressing complexity and social risk factors; focusing on transitions across the care continuum; incorporating the community in intervention design and implementation; population management (i.e., tiering patients by predictive modeling to optimize service delivery); using health information technology tools; reimbursement innovations; and the pressing need for research on evidence-based practice strategies to improve care delivery for PLWMCC. To read the paper in the special journal issue of HSR, go [here](#).
- In *A Mixed Methods Review of Person and Family Engagement in the Context of MCC*, authors Judith Vick, MD, MPH, and Jennifer Wolff, PhD, also found a paucity of evidence-based literature specific to PLWMCC, identifying only a single review specifically addressing engagement issues in MCC. They described a rich body of related work on the shift away from “doctor-centered” care, and the importance of goal setting from the perspective of the patient and family. Notable research gaps included: the difficulty of measuring engagement; strategies for better aligning clinical goals and patient goals; understanding harm resulting from lack of effective engagement addressing health literacy; and the unintended worsening of disparities in pursuing engagement. To read the paper in the special journal issue of HSR, go [here](#).
- In *Health Information Technology to Improve Care for Multiple Chronic Conditions*, authors Lipika Samal, MD, MPH, and David Dorr, MD, MS, explored the potential power of health information technology to bring data, information, and knowledge to improve MCC care, while also

facilitating communication. Focus areas included the recent advances in eCare planning, remote patient monitoring, health information exchanges, and electronic referral tracking. They also underscored the potential harm of health information technology solutions – by adding complexity, fragmentation, expense, and burden – as well as by worsening the “digital divide” that could selectively disadvantage patients with limited access to technology, low health literacy, and limited resources due to low socioeconomic status. To read the paper in the special journal issue of HSR, go [here](#).

#### Available Materials for Plenary Session 4:

- [Bayliss and Savitz pre-meeting video and slides](#)
- [Vick and Wolff pre-meeting video and slides](#)
- [Samal and Dorr pre-meeting video and slides](#)

**Plenary Session 5: Innovative Methods for MCC Research/ Research Methods for Greatest Impact:** In her opening remarks, Dr. Bierman encouraged Summit participants to be bold and innovative in their thinking with regard to methods, including by considering innovative research designs and methodologies, and she stressed the need for research that is rapid-cycle, transdisciplinary, and usable at the point of care. New methods are essential for addressing the challenges of implementing complex interventions within complex care-delivery systems for people with complex medical and psychosocial needs. During the final Day 1 plenary session, Malaz Boustani, MD, MPH, Professor of Medicine at Indiana University School of Medicine and the author of *Agile Implementation: A Model for Implementing Evidence-Based Healthcare Solutions into Real-World Practice to Achieve Sustainable Change*, discussed how new methods are needed to develop the evidence about “what works” to transform MCC care. He presented the “Agile Implementation” approach for solving complex problems. Agile methods explicitly recognize the reality that improving care for PLWMCC will require building systems that can constantly monitor for, and adapt to, variations in the processes of care as well as in the social interactions that are responsible for system performance. As such, they represent an important movement away from traditional research approaches that prespecify an intervention without addressing or adapting to the context in which the intervention is implemented. Furthermore, they rarely include mechanisms to adapt the intervention to increase effectiveness based on continual learning. Agile implementation methods foster the co-design of interventions and the co-production of evidence along with clinician, patients, and caregivers.

In his pre-meeting video and live presentation, Dr. Boustani described the three foundational theories on which he drew in developing the Agile approach (Complexity Theory, Network and Behavioral

Economics) and described the “Agile” eight-step process, which begins with clearly identifying the problem and running short trials of minimally viable solutions or products, with the end goal of creating a minimally standardized operating procedure that can be scaled by adapting the solution to each new environmental and social context. He stressed the importance of involving the user in developing and testing possible solutions to an identified problem by actually observing customers’ experiences and discussing their needs and lives, rather than merely surveying them. Finally, Dr. Boustani reflected on the need for new ways of assessing outcomes and for iterative experimentation and adaptive modifications (“agile implementation”) until the specified goal is achieved. Agile implementation is one of a number of new approaches to conduct research needed to provide the evidence to improve MCC care including rapid cycle evaluation, hybrid trial designs that provide evidence for implementation strategies, adaptive trials, and Sequential Multiple Assignment Randomized Trials (SMART). Looking further into the future, Dr. Boustani envisions transformation through a “smart” system with ongoing feedback and innovative uses of technology and data to promote continual learning and adapting. New technologies and increased patient engagement are necessary ingredients for actualizing this vision, as are empowering the community and leveraging community resources.

**Available Materials for Plenary Session 5:**

- [Boustani Pre-meeting Video](#)

## Small Group Discussions: Helping to Shape an AHRQ Research Agenda for Transforming Care for PLWMCC

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### Small Group Discussions: Overview

Three small group discussion sessions were convened over the course of the 2-day Summit to garner specific input and recommendations from the diverse experts and stakeholders on a future research agenda for AHRQ for transforming care for people with MCC. Participants were divided into seven groups of 8-12 people and led sequentially through three discussions during which they generated, refined, and prioritized 30 specific research questions for future AHRQ-supported research. They were reminded throughout these discussions to consider perspectives and actions needed to address health equity.

***Small Group Discussion Session 1—Identifying Key Research Gaps to Transform Care:*** Each group was assigned to generate a list of research questions from one of the areas addressed in the three commissioned evidence reviews (Patient and Family Engagement, Models of Care, and Health IT). The seven workgroups collectively generated a total of 129 research questions across the three specified domains. AHRQ staff curated these questions and sorted them into 21 cross-cutting categories for refinement and prioritization during Session 2. This curated list is included in the [Appendix](#).

***Small Group Discussion Session 2—Digging Deeper into Proposed Research Topics:*** Seven discussion groups were convened, and each group was assigned two to three broad categories of research questions from the 21 categories that had emerged in Session 1. Participants were asked to *refine* or *reframe* researchable questions from the questions included within their assigned categories and then to *prioritize* the top five of among their revised questions, based on three criteria: responsiveness, impact, and feasibility. A total of 30 refined and prioritized questions emerged from rich and nuanced discussions that ensued, shown in the table below:

## Output From Small Group Discussion #2: Prioritized Topics for Future Research

|    |  |   |
|----|--|---|
| I  | <b>Improving clinical decision-making</b>  | <ul style="list-style-type: none"> <li>• How to improve clinical decision making for patients with MCC?</li> <li>• How can we identify chronic conditions that go together be managed with similar supports?</li> </ul>   |
| II | <b>Optimizing/operationalizing key components of high value care, specifically:</b> <ul style="list-style-type: none"> <li>• Incorporation of patient needs, preferences, and goals</li> </ul> | <ul style="list-style-type: none"> <li>• What is the best process for understanding people’s care management needs and preferences?</li> <li>• How do we develop and use clear and common language so patients and families all understand what we’re all talking about with respect to goal setting?</li> </ul>  |
|    | <ul style="list-style-type: none"> <li>• Patient and family engagement</li> </ul>  | <ul style="list-style-type: none"> <li>• How do you incentivize patient/family/caregivers’ outreach/engagement?</li> </ul>  |
|    | <ul style="list-style-type: none"> <li>• Care coordination/care management</li> </ul>  | <ul style="list-style-type: none"> <li>• What do patients and caregivers say are the biggest problems they face in care coordination, and what are the consequences of those problems?</li> <li>• What are the patterns and causes of discontinuities and fragmentation of care for PLWMCC across diverse populations?</li> <li>• How do systems provide high needs/high risk individuals with better care management, and prevent people from moving into that high-risk category?</li> <li>• How might we redefine the role of the care manager?</li> </ul> |
|    | <ul style="list-style-type: none"> <li>• Provision of whole person care through integration of social and medical care services</li> </ul>   | <ul style="list-style-type: none"> <li>• How can we integrate social, behavioral, and economic factors into the person-centered care plan?</li> <li>• How do we increase visibility of community resources and ensure that people are aware of and understand the services available to them?</li> <li>• How can we integrate social and medical care such that people can seamlessly access the care they need and want, when they need it?</li> <li>• What is the role of community and CBOs in addressing Social Determinants of Health (SDOH)?</li> </ul> |
|    | <ul style="list-style-type: none"> <li>• Involvement and support of caregivers</li> </ul>  | <ul style="list-style-type: none"> <li>• What are the effective methods of assessing caregiver challenges, goals, and needs?</li> </ul>   |
|    | <ul style="list-style-type: none"> <li>• Use of digital health/HIT tools</li> </ul>  | <ul style="list-style-type: none"> <li>• How can we optimize the use of technical IT (including telehealth) in PLWMCC?</li> <li>• How do we use technology to create a better information ecosystem for PLWMCC, from collection to personalizing care?</li> <li>• How can we better capture information provided by patients and families into the EHR as well as function and caregiver measures, and link those data across our health</li> </ul>   |

|            |                              |  |
|------------|------------------------------|--|
|            |                              | <p>systems to prevent duplicate collections of information by different providers?</p> <ul style="list-style-type: none"> <li>• How can information technology support the implementation of care plans for PLWMCC to best support their goals of care?</li> <li>• How can health IT support shared decision-making to prioritize care that meets patient goals?</li> <li>• Can we develop, test, and implement risk stratification and decision support tools?</li> <li>• How can we modify EHRs that are problem oriented and not optimal for supporting MCC including SDOH and disparities of care?</li> <li>• How can we better use interactive consumer or healthcare specific technologies for individuals and caregivers to help them with self-management of care, while protecting users' privacy and safety?</li> <li>• How might we leverage remote patient monitoring in implementing cost-effective and patient-centered care?</li> <li>• How do we increase the literacy of providers with respect to HIT use and implementation?</li> </ul> |
| <b>III</b> | <b>Design and workforce</b>  | <ul style="list-style-type: none"> <li>• What methods build provider skills in whole person care?</li> <li>• How can we optimize use of homecare in PLWMCC?</li> <li>• How do we train providers to be holistic?</li> </ul>  |
| <b>IV</b>  | <b>Foundational Research</b> | <ul style="list-style-type: none"> <li>• How do we develop quality measures to support MCC?</li> <li>• How to we identify meaningful outcomes, measure them, and use them in care?</li> <li>• How can the stakeholder/patient perspective inform interventions that would be efficient from the healthcare perspective?</li> </ul>   |

**Small Group Discussion Session 3—Putting it All Together to Transform Care:** Participants were reassigned across seven new discussion groups and asked to develop examples of overarching, multi-component initiatives by seeking natural linkages and/or innovative ways to combine or expand on research questions from 30 research questions that had been shortlisted during Session 2. Participants were invited to include any additional concepts or topics that could be needed to contribute to the success of these initiatives.

A total of eight examples of multi-component initiatives for AHRQ consideration emerged from this session as further described below. The importance of developing the capacity and evidence needed to achieve health equity was a cross cutting theme for all eight of these proposed initiatives. Additionally, the importance of developing these in the context changed healthcare environment and health needs in the wake of the COVID-19 pandemic was emphasized.

## Output from Small Group Discussion #3

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**Eight examples of potential multi-component initiatives emerged from the third set of the seven small groups discussions:**

1. *Identify and investigate the usability and impacts of models of care that enable care teams and patients to leverage emerging technologies to advance coordinated, continuous, comprehensive care for PLWMCC in ways that measurably improve patient-centered and policy outcomes (Person-Centered Primary Care Measure (PCPCM), Utilization, Costs, Access across settings and for all patients, including culturally diverse patients and those having limited resources and/or limited access to the web).*
  - How can new models for care delivery, which take advantage of new forms of technology avoid the attendant risks of increasing, rather than reducing, fragmentation of care and disparities in care access and quality?
  - How can co-design best be used to support the development of appropriate new care models for PLWMCCC?
  - How can the new technologies support the gathering of patient and population health data and support clinical and/or shared decision-making about appropriate care options?
2. *Improve tools and methods for more effectively identifying, capturing, and understanding the individual's goals and preferences, and re-structuring care delivery to focus on them, rather than on the constellation of diseases he or she presents. Doing so will require:*
  - Identifying the most effective methods for identifying needs and preferences; use of user-centered design.
  - Developing clear language to support care planning and of distinguishing between current care plan goals, versus future plan goals. Need to anticipate need for different plans reflecting different goals for different life stages.
  - Identifying methods and approaches for addressing limitations and challenges associated with evidence-based medicine and use of clinical guidelines for PLWMCC.
  - Identifying ways to address barriers and challenges associated with overspecialization for commonly co-occurring problems, for example, use of a navigator to integrate the recommendations of subspecialists.

3. *Test and demonstrate effective, integrated models of interdisciplinary care, with particular attention to address challenges to doing so within the context of increased movement to virtual care. Investigations and demonstrations should:*
  - Pay particular attention to addressing challenges to integrated, interdisciplinary care within the context of increased movement to virtual care (increasingly spurred by the pandemic), including but not limited to exacerbation of disparities.
  - Expand beyond inclusion of behavioral health clinicians to dietitians, pharmacists, and social services.
  - Focus on empowering the patient to feel capable of self-management and engage in shared decision making with team members.
  - Identify measurable outcomes that can be used to assess the quality of these different models.
4. *Develop and test methods for increasing functionality, usability, and interoperability of the EHR to:*
  - Improve its use as a tool for improved communication across the care team, and with patients and families;
  - Reduce fragmentation and improve care continuity;
  - Better capture and codify patient data in ways that will support shared decision-making.
5. *Strengthen use of predictive modeling, informatics, and data science to identify those at high risk and rising risk and strengthen CDS and care plan development to address identified risks. In doing so,*
  - Address anticipated implementation challenges to sustained use by clinicians using rapid-cycle real world testing.
  - Investigate effectiveness and impact of use predictive models in supporting patient engagement and shared decision-making.
6. *Expand interoperability and data sources for EHRs to improve whole person care and reduce disparities and test impacts on care outcomes for PLWMCC.*
  - Identify specific types and sources of data that are essential for providing whole person care, supporting shared-decision-making, and addressing a patient's goals and strengths.
  - Capture information from multi-professional teams, SDOH, home environment, status of caregivers, patient-reported information from apps.
  - Identify methods for intelligible and meaningful data synthesis and presentation.



7. *Replace provider-centric care plans with patient-centric care plans to support coordination of care across primary care, specialty care, and community-based organizations. Doing so will require:*
- Engaging patients and their primary caregivers in the process of the care plan development and goal setting.
  - Awareness of and attention to context, custom and practice that have sustained the current provider-centric bias (e.g., evidence-based standards, payor mandates, workflow considerations).
  - Assessment of recently-validated innovations that may be suitable for broader dissemination and implementation, including: use of newer, cutting-edge, patient-centered quality measures that focus on both experience and outcome; training clinicians in the vocabulary of goal-setting with patients and families, with standardized exploration of cultural differences, health literacy, equity, and spiritual needs; embedding regular “goal reconciliation” into routine clinical care with the same diligence with which we carry out medication reconciliation; restructuring patient encounters, such as the office visit or home visit, to allow time to discuss patient values; and refining electronic care plans to bridge the gap between documentation and action.
8. *Develop a common “operating language” or nomenclature for SDOH and community resources, analogous to the way we code for diseases and medical procedure, that could:*
- Assist in quantifying concepts like housing, food security, and environmental safety.
  - Mitigate challenges that arise when vital community service organizations work in isolation.
  - Enable cross-platform linkages between patient needs and effective solutions.

## Closing Remarks and Next Steps

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In a brief final plenary session, Dr. Bierman thanked participants for their active and engaged participation, particularly in the context of meeting virtually. She reiterated the belief expressed during the Summit that transformation of care for PLWMCC will require significant reengineering of the healthcare system. She communicated AHRQ's interest in receiving grant applications in response to its [Special Emphasis](#), expressing AHRQ's particular interest in grant applications focused Optimizing Care for People Living with Multiple Chronic Conditions through the Development of Enhanced Care Planning. The Fall 2021 publication of a special issue of *Health Services Research* (HSR) titled *The Science of Care for People with Multiple Chronic Conditions* will include an [AHRQ Research Agenda for Transforming Care for PLWMCC](#)--shaped by the invaluable wisdom and input of the Summit participants--along with evidence reviews and papers from an open call. The summit underscored that transforming care for PLWCC is central to improving the patient-centeredness, effectiveness, efficiency, and sustainability of the U.S. system. Importantly, changes put in place to improve MCC care will benefit all.

## Appendix: Proposed Topics for MCC Research from Session 1

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### Care Coordination/HIT

1. How can we use technology to support the sharing of information and management for people with MCC across providers and settings of care (health information exchange, evidence-based practice and interoperability of various EHRs)?
2. How can we use technology to support the sharing of information and management for people with MCC, their family, and caregivers with their care team (health information exchange, evidence-based practice and interoperability of various EHRs)?
3. How can IT support care aligned with patient goals across the continuum from the medical domain through home health and LTSS services?
4. How can IT support care coordination and continuity with home health during care transitions with respect to referral, timeliness of home health visits, safety, and quality?
5. How do we create a one-stop-shopping tool for PLWMCC and their families to access health and social resources in the community?
6. How can information systems better provide a picture of a PLWMCC rather than a collection of diseases (or ICD-10) codes that identify them as a person with MCC?

### Care Coordination

1. How do we increase uptake of CMS incentives for more meaningful chronic care management to improve coordinated approaches to care?
2. Who is accountable for what is happening?
3. How do we coordinate care across the continuum of care instead of delivering care in siloes?
4. What do patients and caregivers say are the biggest problems they face in care coordination and what are the consequences of those problems? What are their ideas for fixing these issues?
5. How do different care providers intersect and interact with each other within and across systems?
6. How can specialty care providers do a better job of coordinating MCC care?
7. Can we develop tools to better link provider and social resources? And for primary care to hospitals and specialists?
8. What do patients and caregivers say are the biggest problems they face in care coordination and what are the consequences of those problems? What are their ideas for fixing these issues?
9. How can different care providers effectively intersect with each other within and across systems?

### Care Coordination/Models of Care

1. How do we implement interprofessional team-based care when payment incentives are a big obstacle?
2. How can we support people living with MCC in making decisions and self-management when they receive conflicting recommendations from different providers? How do we foster trust in the face of conflicting recommendations?

### Continuity of Care

1. What are patterns and causes of discontinuities of care for people living with MCC? What interventions could reduce discontinuity of care for those patients?
2. How do you manage patients' transitions between insurers to avoid continuity of care disruption?
3. What is the relationship between care continuity and cost, utilization, outcomes?

## Care Planning

1. How comfortable are patients with MCC with co-generating and evaluating their care plan with the care team? What is needed to support this process?
2. How might we rigorously measure care plan's patient-centeredness for patients with MCC?
3. How do you effectively get evidence to the point of care for patients and for providers?
4. How could the intersection of interdisciplinary care plans be supported by CDS?
5. How can we leverage big data and health IT to better understand what care will work best for someone based on their social and medical context? What can predictive modeling/machine learning contribute to the creation of eCare plans that support personalized care according to patient family history, social determinants of health, genetic information, and preference?
6. Can effective shared decision-making be used as a way to enhance trust? Or does effective shared decision-making rely on there already being trust?
7. How do we prioritize conditions among multiple chronic conditions for treatment? How to weigh competing treatment, evidence?
8. What are the actionable social risk factors that we need to focus on for MCC?
9. What is the impact of giving people/patients boot camp for how they can advocate with caregivers?
10. How do we harness data to make rational use of it to inform care and improve outcomes?
11. How do we prioritize conditions among multiple chronic conditions for treatment? How do we weigh competing treatment, evidence?
12. How do you prioritize treatment options and determine which providers' patients should see?
13. How can tools used for SMD and CDS be developed to incorporate not only clinical conditions but also important factors from the person's life and environment?

## Care Planning/Goal Setting

1. What language is necessary for communication strategy for a primary care healthcare system to start re-framing around person goals: (a) prevention of premature death and disability, (b) maintenance and enhancement of quality of life, (c) personal growth and development, and (d) a good death?
2. How do we use common language so patients/families all understand what we're all talking about with respect to goal setting?
3. How can health IT support shared decision-making about care that prioritizes patient goals in terms of length of life, quality of life, simplicity, dignity, and comfort? In terms of inequity, what are the design, educational or other approaches that will allow all people living with MCC to use these tools?
4. Focusing on quality of life rather than longevity, how do we assess questions important to patients? How goal concordant was your care per year? From the patient's perspective, did you reach your goals?
5. How do we support effective self-management?
6. PLWMCC are a diverse group with diverse needs. How can we identify ways to best match each individual with the types of care, support and services they need to achieve their goals?

## Care Management

1. How do we use interactive technologies such as Alexa for medication reminders? How do we do this while addressing privacy concerns?
2. How do provide high needs/high risk individuals with better care management?
3. How do we manage steps in step care?

## Virtual Care/Care Outside the Office

1. Can we use a digital forum and online community to fill the gap of care outside the doctor's office?
2. How can we use technology support people living with MCC to improve their functional status?
3. How can we co-design IT solutions to facilitate patient/caregiver/provider activation, engagement, and co-production of health?
4. How might we leverage remote patient monitoring to engage patients with MCC in implementing cost-effective and patient-centered care?
5. How do we address disparities in IT availability or literacy, which can be related to health equity, disability, or even advance age? What interventions, learnings, coaching, infrastructures need to be developed?
6. How do we enable and partner MCC patients to develop and implement technology (e.g., smart phones, or other API based programs) that fosters engagement with providers?
7. What is the role of wearables, remote monitoring devices, etc.?
8. What is the role of telehealth on people living with MCC? Under what circumstances is telehealth not appropriate for MCC patients? Dosage of telehealth/digital visits for chronic disease management?
9. What technology is needed for hospital at home?

## EHR Design

1. How do we effectively implement EHRs to support patient-centeredness including photos and bios?
2. For people with MCC (P), how does goal directed documentation/organization within an EHR display to all clinicians (I) versus traditional problem lists or Problem Oriented Medical Record (POMR) documentation (C) affect both patient and provider behaviors/actions and outcomes (O)?
3. How do we increase the literacy of providers with respect to HIT use and implementation? How do we design EHR/HIT applications to be user friendly and support care?
4. How do we insert fields into our EHRs to capture function, caregiver measures, take advantage of patient/family information and figure out ways to link those data across our healthcare system so they don't have to give the same information to multiple providers?
5. How can we modify EHRs that are problem oriented and are not optimal for supporting MCC care to include social determinants of care and disparities of care? Need ways to identify who is at risk, and how do we best use limited resources?
6. How should genomic medicine be integrated into EHR?

## Integration/Social and Medical Care

1. How can we better integrate social and medical care such that people can seamlessly access the health or social care they need (and want) when they need it and that this care can be informed by the person's complete social ecological context?
2. How can providers expand their capacity to serve the mental health needs of PLWMCC?
3. What is the most effective way to integrate medical care with psycho-social supports and community resources to meet social needs?
4. What is the mental and behavioral health impact on PLWMCC of the COVID-19 pandemic and implications on models of care?
5. How can the intersections between physical and behavioral health be improved?
6. What do primary care providers need to be able to attend to physical, mental, and behavioral health needs? Is primary care where mental and behavioral health needs should be addressed?

7. How can providers expand their capacity to serve the mental health needs of people living with MCC?
8. What is the mental and behavioral health impact of the COVID-19 pandemic on people living with MCC and implications on models of care?

### **Community Linkages**

What is the role of community and community organizations in addressing the social determinants of health? How do we link these efforts with care delivery?

### **Primary Care**

1. How might health systems better support primary care providers in delivering patient-centered MCC care?
2. How do we support primary care practices in adopting to changing needs and crises, e.g., COVID-19, rapid adoption of telehealth?
3. How do you incentivize prevention?
4. How do you spread and scale facilitation to help practices?
5. Does increased use of team care and prospective payment improve patient reported outcomes?
6. How can models be more specific about roles of team members (who can do what based on their background)?
7. How can we learn from real world examples of what is working including models within the U.S. and from other countries? (i.e., bringing primary care into community and maintaining functioning)
8. Currently the workflow in primary care is best suited for single disease management or addressing acute conditions. Are there ways the workflow can effectively be changed to better meet the needs of PLWMCC?

### **Engagement**

How do you incentivize patient outreach/engagement?

### **Data to Inform Care**

Should we use data that are out there, being sold in the digital market to know about individuals, such as marketing, Google ads, purchasing behaviors, about credit card data? Could these data be used to do predictive modeling to support health and care for MCC (e.g., medication adherence)? How could privacy issues be addressed? What would be the impact on health equity/disparities?

### **Measurement/Outcomes**

1. What are important measures for those different subgroups of PLWMCC?
2. How do we identify meaningful outcomes for PLWMCC, measure them, and use them in care?
3. How useful are current measures of MCC in caring for patients? To what extent do they tell providers what patients' lives are like?

### **Healthcare Design**

1. How can the stakeholder/patient perspective inform interventions that would be efficient from the healthcare perspective?
2. Team care is identified as being beneficial for supporting individuals with chronic conditions or complex disease (e.g., palliative care teams). How can we identify the factors of team care that lead to improved outcomes for PLWMCC?

### **Costs/Return on Investment**

1. Which models of care for MCC generate cost savings? For whom and under what conditions?
2. What are the costs of care to PLWMCC and caregivers?
3. How do we maximize the return on the significant investment that PLWMCC and caregivers make in taking care of chronic conditions?
4. What are key mechanisms for implementing and scaling effective models of care -- Incentives/ROI? Workflow? Payment? Measurement?

### **Caregiver Needs**

1. How can systems/providers reduce the burden on caregivers and sustain caregiver health and wellness?
2. How do we assess the burdens, needs and goals of caregivers?
3. How do we identify differing needs of caregivers and patients and reconcile them when they differ?
4. Review evidence to date, needs systematic review to see what has been done to date; reframing to instead of talking about stressed caregiver (this is the terminology that APA uses); move away from stigmatizing language; is this paid or unpaid caregivers?

### **Home Care**

1. What is the role of home healthcare on the management of multiple chronic conditions? How do we optimize its impacts? How do we determine its role across people living with MCC with different needs?

### **Long-Term Care**

1. What is the role of long-term care services in care of patients with MCC?

### **Whole Person Care**

1. How can we improve current data we have to capture all domains that are not in our records, e.g., SES factors and history of past medical conditions?
2. How do we make care simpler so people and their families can understand it?
3. Screening for adverse childhood effect, trauma informed care, how does that impact MCC? Can they be included as life stressors in general, e.g., PHQ 4 or 9 as screener to refer behavioral health services. Maybe underutilized. How do we integrate into clinical workflow, whole person care?
4. People with multiple social risks, what's the tipping points, who makes them resilient, versus worse outcomes?
5. How are people with MCC on Medicaid being negatively affected by Medicaid requirements -- work, income, life requirements?
6. Person-centered care requires listening to and understanding the individual's goals and preferences. How do we effectively incorporate those goals and objectives in determining the corresponding outcomes of care and whether those outcomes were attained?
7. What methods are needed to provide clinicians and providers with the skills to effectively support whole person care?
8. How can we effectively integrate social, behavioral, and psychosocial health factors into the concept of person-centered care for PLWMCC?

### **Workforce Training**

1. How do we train providers to be holistic?