High-Level Research Question

What aspects of empowering care management lead to better patient-centered outcomes for patients with ongoing complex healthcare needs?

Assignment for Workgroup Participants

- Based on your perspective (patient, clinician, payer, etc.), what are two or three of the most relevant comparative effectiveness research questions focusing on empowering care management for people with ongoing complex healthcare needs? Questions should address current gaps in knowledge.

- Present and discuss your research questions on the day of the workgroup meeting. This should take no longer than 5 minutes total for each presenter. Slides with your questions will be prepared in advance of the meeting.

“This document was prepared for informational purposes only and should not be construed as medical advice or used for clinical decision making.”
I. Introduction

A majority of Americans – 50.9% – now manage at least one chronic health condition; a quarter of Americans have multiple chronic conditions; nearly 5% of people in the United States manage four or more separate conditions. About one-quarter of people living with a chronic condition have one or more limitations on their activities of daily living (such as difficulty dressing, bathing, or eating). Seven out of 10 American deaths annually are the result of a chronic disease. [CDC, 2013; Ward, 2010]

Chronic diseases are typically managed, not cured. Patients and their caregivers manage them with assistance, education, and acute, preventive, and ambulatory care. Often these services are performed by several providers located in different settings. Overall, care for chronic diseases is fragmented and hard for patients to navigate.

As chronically ill patients face a growing number of interactions with healthcare systems, they run a greater risk of experiencing poor outcomes. The disjointed and duplicative care these patients experience can lead to direct harm, medication errors, decreased ability to manage conditions, and increased total and out-of-pocket costs. To overcome the challenges associated with complex chronic conditions, patients, caregivers, and providers must work as partners to achieve the best outcomes possible. Furthermore, respect for patient values and cultural norms are essential to developing a successful partnership.

II. Terminology and Definitions

Generally, there is no agreed-upon definition of patient empowerment among researchers. However, common elements and evolving theories on patient-centeredness have provided a working definition.

*From the patient perspective:* Empowerment is a process of growth that typically involves education and social support networks; it is an alternative to compliance. Empowered patients should be able to reconcile the diagnosis of one or more chronic conditions with their own identity, purposely gain or limit knowledge of their condition(s), gain some sense of control over their condition(s), and participate in care decisions. Some studies also show empowered patients to be more sensitive to other patients and to demonstrate an increased willingness to help those in a similar position. [Small, 2013] Empowered patients typically ask their providers more questions, are more involved in their care, rate their experience with providers more highly, and have fewer reported instances of feeling “powerless.”

*From the provider perspective:* Patient empowerment is “helping patients discover and develop the inherent capacity to be responsible for one’s own life.” [Funnell, 2004] It is a process of communication and education in which knowledge, values, and power are shared. Generally the provider works with the
patient to create the partnership that will characterize care moving forward – helping the patient determine his/her role in self-care as well as in developing goals for care.

*From the health system perspective:* Empowered patients should be more able to manage their condition outside the hospital setting, thus using fewer services and decreasing the likelihood of an unplanned hospitalization.

*From the payer perspective:* Empowered patients should be value-driven consumers who require fewer interactions with providers – a patient who thoroughly participates in his or her own care should not only discourage inefficient care, but also seek out providers/specialists with better-quality ratings.

**Possible Examples of Characteristics of Patient-Empowering Care Management (PECM) include the following:**

- Strategies designed to make patients the center of care by encouraging them to participate in decisions and management of their care.
- Patients determine and set care goals in collaboration with their care provider(s).
- Patients receive education about their disease, options for treatment and management, including side-effects, and mid- and long-term outcomes of their diagnosis.
- Patients receive counseling to build confidence, self-efficacy, and trust with a care manager (physician, nurse, social worker, case manager, or other personnel fulfilling this role).
- Practitioners receive specialized training in methods of care management.
- Patients are linked with social support networks such as peer patients or support groups, to help both themselves and others.
- Providers in the care process coordinate their efforts, educate the patient and caregivers, reconcile medications, and make logistical arrangements for appointments and community referrals.

**III. Possible Examples of Patient-Centered Outcomes**

- Health & well-being
- Achievement of patient-negotiated care goals
- Quality of life
- Functional status
- Patient satisfaction
- Caregiver strain
- Confidence, sense of control
- Medication discrepancy or error
- Knowledge (medication or other)
- Adverse events
- Mortality
IV. Care Models

There are a large number of published studies and ongoing program evaluations of care management models, for both general chronic disease management and specific diseases. Recent systematic reviews show that care management techniques generally demonstrate inconsistent effectiveness; some models work in some settings with some populations.

The models of care management that focus on self-care and systematic clinical support have shown promise in improving patient-centered outcomes. Models such as the Care Transitions Intervention, Guided Care, and the Stanford Model of Chronic Disease Self-Management use different approaches, but have similar goals of helping patients manage their own care better. Overall, there is a need for additional research with increased specificity in study design and continued model development in order to find better ways to deliver effective, coordinated care.

V. Supporting Innovations

There is an increasing awareness of the rising burden of chronic diseases and the social, epidemiologic, and demographic changes that will make these even more prevalent in coming years. The passage and implementation of the Affordable Care Act, provisions within the American Reinvestment and Recovery Act, and numerous other government and private efforts show a widespread policy commitment to improving outcomes by putting the patient at the center of care. The World Health Organization is focusing on empowerment as “an important element of human development. It is the process of taking control and responsibility for actions that have the intent and potential to lead to fulfillment of capacity. This incorporates four dimensions of: self-reliance; participation in decisions; dignity and respect; and belonging and contributing to a wider community.”

These developments have coincided with an increasing number of publications on empowerment, activation, enablement, engagement, shared decision making, choice architecture, etc. Researchers and clinicians are continuing to build upon previous research in response to changing policies and increasing demand from patients and other stakeholder groups. Among the new ideas under development are inventive ways to conceptualize and measure empowerment and how it fits into care management.

VI. Some Questions to Be Answered by Comparative Effectiveness Research (CER)

- How do different model elements and constructs of PECM, such as care setting, patient education and counseling approaches, and implementation of shared decision making within the framework, affect outcomes that matter patients?
- How does PECM affect measures of patient-centered outcomes, including those important to caregivers, using evidence-based, validated tools?
What are the differences in outcomes based on population characteristics such as age, sex, race, ethnicity, socioeconomic status, comorbid conditions, health literacy, and access to different care settings?

How does one implement empowering care strategies in real-world settings?

What is the best way to target empowering care to specific patient-centered outcomes that are most relevant for each patient? And how does one shape the care management teams accordingly?

What is the impact of low English proficiency and poor health literacy on care management approaches?

VII. Facilitators of and Barriers to Implementation

FACILITATORS

- Significant impact for all complex chronic disease patients and their caregivers.
- Increasingly educated and involved patients and caregivers in care.
- Changing demographics – the aging U.S. population.
- Insurers showing flexibility in payment models (Patient Centered Medical Homes, Accountable Care Organizations, Depression Improvement Across Minnesota, Offering a New Direction (DIAMOND) model of integrated care).

BARRIERS

- Lack of time for medical providers to work with patients.
- Structural inability of care providers to communicate in an efficient and streamlined way.
- Insufficient resources, including additional personnel or services.
- Organizational inflexibility to implement new care strategies.
- Difficulty in changing attitudes in health practices to center care around the patient.

VIII. Conclusion

There is significant opportunity to conduct new research on PECM that focuses on outcomes that matter to patients and caregivers. However, the difficulties related to culture change in practice, resource restrictions, and other barriers to implementation must be taken into consideration. Research that includes strategies for adoption of successful patient-empowering care models in practice has the greatest potential for widespread implementation.

While some models of care management show success in improving patient-centered outcomes, little is known about what aspects of models work best for specific patient subpopulations. There is a need to develop measures and models related to this way of providing care. By bringing together researchers, practitioners, patients, and caregivers we can establish a common set of definitions so that discussions can involve all stakeholders.
IX. References


