MEETING FOCUS: CONSIDERATION OF A GUIDING FRAMEWORK FOR A CULTURE OF PATIENT- AND FAMILY-ENGAGED CARE.

Core questions:
1. What are levers and opportunities for patient and family leaders and system executives to use care culture as a tool to advance health outcomes?
2. What lessons can be gleaned from experiences to date with patient and family engaged care culture?
3. Where is there opportunity to advance the evidence base for patient and family engaged care?

Outcomes intended: Strategies to use the framework as a tool for patient and family leaders and health system executives to advance PFEC in individual hospital systems; understand promising approaches to engaging patients and families in culture change efforts; identify opportunities for collaborative projects to make progress on the evidence base for PFEC.

REPRESENTATIVE OBSERVATIONS
- The forthcoming discussion paper Harnessing Evidence and Experience to Change Culture: A Guiding Framework for Patient and Family Engaged Care provides a common understanding of essential elements for creating and sustaining patient and family engaged care culture. (SF)
- To advance an evidence base for PFEC, great weight must be given to qualitative measures; patients hold the ultimate power as relates to their health, but there is a leadership imperative in creating a culture to engage patients. (MH; no slides)
- PFEC is about development and maintenance of relationships; successful implementation requires successful organizational and clinical dynamics, tools to support culture change, alignment of external drivers, and wider breadth of evidence on “recipes” for success. (ML; no slides)
- PFEC requires mindset shift, so for clinicians this may require a “field guide toolkit” focused on clinician education on empathy, tools for clinicians to facilitate PFEC behaviors, and assessment tools for measuring clinician competencies. (KD; no slides)
- PFEC at the health system level will require building a business case that closes the gap between the PFEC and c-suite value equations, and creating a bridge to national PFEC goals that link to payment and accreditation. (SP; no slides)
- Intermountain has addressed dehumanization in the ICU by removing visiting restrictions and instituting family rounding and procedural presence, as about 50% of families want to be with patients during procedures. In addition, work is underway to develop predictive models to tailor care dependent on care trajectories, expected outcomes and family and team dynamics. (SB)
- Themes from effective care models for advanced illness builds on existing resources in community; links community and clinical resources, and; delivered by interdisciplinary, team-based care model. C-TAC aims to build a movement by addressing key components of collective impact: common agenda; shared measures; mutually reinforcing activities; continuous communication, and; backbone support. (DL)
- Sutter Health’s Advanced Illness Mangement model has expanded to serve 3,000 people daily and incorporates 5 care pillars: advance care planning, red flags and symptom management plans, medication management, follow up visits and patient engagement and self-management reports. The model has exceeded goals for satisfaction (90%+) and cost savings (estimated at $60 million) over 3 years of a CMMI grant. (MR)
- Coproduction of healthcare services invites us to: help patients and families be better partners; help health professionals be better partners; make partnership a core value in the design and improvement of healthcare service systems; connect healthcare service outcomes to outcomes that matter to patients and families; and; innovate at the boundaries between the healthcare service system and the wider community. (MB)
- HealthExperiencesUSA.org is a collaborative effort to gather a broad range of patient narratives using rigorous qualitative research methods. The methodology is used in 12 countries and for each module researchers conduct 40-50 interviews with a diverse set of patients recruited through a range of avenues (maximum variation) and interviews continue until no new ideas or experiences are voiced (saturation). (RG)
- The AHRQ Innovations Exchange PFCC Learning Community linked 11 hospitals in Florida that serve 50% of the state population to support implementation of PFCC strategies and found leadership support and involvement, dedicated person to lead efforts, and bringing together directors and managers from similar departments with similar goals facilitated the learning process. (BI & KS)

COLLABORATIVE ACTIVITIES FOR CONSIDERATION
The development of NAM discussion papers and/or exploratory meetings on the following topics:
- Advancement of Patient and Family Engaged Care. Develop common PFEC action agenda including the creation of national PFEC goals. Develop a crosswalk of PFEC standards and measures and determine ways to digest the framework into messages for various stakeholder groups.
- Compendium of innovations. Explore characteristics of organizations that have set a vision for PFEC.
- Reaching the C-suite. Explore the value proposition for the c-suite to implement PFEC; develop messages and tools for executives, perhaps looking to other fields for guidance.
- Framework for holistic measurement. Using Vital Signs framework, explore methodology for integrating social data and social determinants in EHRs and develop strategies to align physician and patient goals and targeted health outcomes.
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CARE CULTURE AND DECISION-MAKING COLLABORATIVE

Organizations Participating

Consumers United for Evidence-Based Healthcare
Kaiser Permanente

C.S. Mott Children’s Hospital
Lown Institute

Dana-Farber Cancer Institute
Mayo Clinic

Dartmouth Center for Health Care Delivery Science
National Association of Community Health Centers

Dell Children’s Medical Center
National Business Group on Health

Emory University
National Committee for Quality Assurance

Family Voices
National Governors Association

Georgetown University
National Partnership for Women & Families

George Washington University
National Quality Forum

Georgia Regents Medical Center
Nemours Health System

Gordon and Betty Moore Foundation
Northwestern University

Health Dialog
NYU Langone Medical Center

Healthwise
Oregon Health & Science University

Henry J. Kaiser Family Foundation
Patient-Centered Outcomes Research Institute

Informmed Medical Decisions Foundation
Patient-Centered Primary Care Collaborative

Institute for Healthcare Improvement
PatientsLikeMe

Institute for Patient-Centered Care
PFCCpartners

Johns Hopkins Health System
Planetree

Josiah Macy, Jr. Foundation

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Intermountain Healthcare

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Distribution to colleagues is encouraged. Additional information at: www.nam.edu/leadershipconsortium.