

## CARE CULTURE & DECISION-MAKING INNOVATION COLLABORATIVE

December 7, 2016 Meeting Highlights

**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. ([SE](#))
- 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 Magement 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. ([BJ & 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.
- *Clinician satisfaction & engagement.* Explore impact of PFEC on clinician satisfaction and strategies for clinician education on patient engagement.
- *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.



THE LEARNING HEALTH SYSTEM SERIES

## PARTICIPANTS

Mary Naylor (Penn; Co-Chair), Bill Novelli (Georgetown and C-TAC; Co-Chair), Maren Batalden (Cambridge Health Alliance), Jennifer Bires (GW), Meryl Bloomrosen (AAFA), Cindy Brach (AHRQ), Samuel Brown (Intermountain), Mayr Budny (Care Goals), Jim Burrows (Nemours), Kristin Carman (AIR), Laura Castellanos (AHA), Mary Chesney (University of Minnesota), Keri Christensen (NCQA), Mary Jo Deering (MITRE), Karen Drenkard (GetWellNetwork), Sylvia Fisher (HRSA), Nancy Foster (AHA), Susan Frampton (Planetree), Liza Fues (GW), Leslie Kelly Hall (Healthwise), Libby Hoy (PFCCpartners), Janice Genevro (AHRQ) Rachel Grob (University of Wisconsin), Martha Hayward (IHI), Noelene Jeffers (Unity Health Care), Bev Johnson (IPFCC), Christina Johnson (American College of Nurse-Midwives), Martin Kohn (Sentrian), Megan Lewis (RTI), David Longnecker (C-TAC), Tara Montgomery (Consumer Reports), Wendy Nickel (ACP), Lyn Paget (Health Policy Partners), Bryan Parker (Universal Hospital Services), Sherry Perkins (Dimensions Healthcare System), Gloria Plottel (GSPsquared), Mandi Pratt-Chapman (GW), Monique Reese (Sutter Care at Home), Lee Rucker (Enhance Value), Allison Sandera (Florida Hospital Association), Juliette Schlucter (NYU), Joel Seligman (Northern Westchester Hospital), Sue Sheridan (CMS), Melissa Simon (Northwestern University), Sheila Snoddy (C-TAC), Kim Streit (Florida Hospital Association), Paul Tang (IBM Watson Health), Megan Tschudy (Johns Hopkins School of Medicine), Carol Wahl (CHI Health Good Samaritan), Blaine Warkentine (Vimty).

## CARE CULTURE AND DECISION-MAKING COLLABORATIVE

### *Organizations Participating*

AARP	Consumers United for Evidence-Based Healthcare	Kaiser Permanente	RAND Corporation
American Academy of Nursing	C.S. Mott Children's Hospital	Lown Institute	Research!America
American Academy of Pediatrics	Dana-Farber Cancer Institute	Mayo Clinic	Robert Wood Johnson Foundation
American Academy of Physician Assistants	Dartmouth Center for Health Care Delivery Science	National Association of Community Health Centers	Schwartz Center for Compassionate Healthcare
American College of Clinical Pharmacy	Dell Children's Medical Center	National Business Group on Health	Sentrian
American College of Nurse-Midwives	Duke University	National Committee for Quality Assurance	University Hospitals
American Hospital Association	Emory University	National Governors Association	University of North Carolina
American Institutes for Research	Family Voices	National Partnership for Women & Families	University of Pennsylvania
American Medical Association	Georgetown University	National Quality Forum	University of Washington
American Nurses Association	George Washington University	Nemours Health System	Vidant Health System
Association of Academic Health Centers	Georgia Regents Medical Center	Northwestern University	Virginia Commonwealth University
Association of American Medical Colleges	Gordon and Betty Moore Foundation	NYU Langone Medical Center	Federal agencies:
Asthma and Allergy Foundation of America	Health Dialog	Oregon Health & Science University	U.S. Dep't of HHS
Beryl Institute	Henry J. Kaiser Family Foundation	Patient-Centered Outcomes Research Institute	- AHRQ
Blue Shield of California Foundation	Informed Medical Decisions Foundation	Patient-Centered Primary Care Collaborative	- HRSA
Boston Children's Hospital	Institute for Healthcare Improvement	PatientsLikeMe	- NIH
Braintree Rehabilitation Hospital	Institute for Patient- & Family-Centered Care	PFCCpartners	- CMS
C-Change	Johns Hopkins Health System	Planetree	- ONC
Cincinnati Children's Hospital	Josiah Macy, Jr. Foundation		- CDC
Coalition to Transform Advanced Care			U.S. Dep't of Defense
Consumers Union			U.S. Dep't of VA

## THE NAM LEADERSHIP CONSORTIUM FOR A VALUE & SCIENCE-DRIVEN HEALTH SYSTEM

<b>Chair</b>	Gary Kaplan Virginia Mason Health System	Richard J. Pollack AHA	Debra B. Whitman AARP
Mark B. McClellan Duke University			
<b>Members</b>	Gregory F. Keenan AstraZeneca	Peter J. Pronovost Johns Hopkins Medicine	<b>Ex-Officio</b> AHRQ Andrew Bindman
David Blumenthal The Commonwealth Fund	Darrell G. Kirch AAMC	Murray Ross Kaiser Permanente	CDC Thomas Frieden Chesley Richards
Paul Chew Sanofi US	Richard E. Kuntz Medtronic	John W. Rowe Columbia University	CMS Andrew Slavitt, MBA Patrick Conway
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Paul Grundy IBM	Jonathan B. Perlin HCA, Inc.	Marta Tellado Consumers Union	
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