



CARE CULTURE & DECISION-MAKING INNOVATION COLLABORATIVE

December 2015 Meeting Highlights

Meeting goal: STRENGTHENING STRATEGIC PRIORITIES FOR A PATIENT- & FAMILY-CENTERED CARE CULTURE

Topics

- 1) **Measuring progress** in a patient- and family-centered care culture
- 2) **Assessing the impact** of patient and family initiatives: the evidence
- 3) **Tools** to inform decision-making

Representative observations

- Aiming to move from general measures of experience to the greater specificity of goals, tools such as CollaboRATE focus on the patient perception of care match with patient goals (DF).
- Work is underway to at Massachusetts General Hospital and the Informed Medical Decisions Foundation to develop decision quality instruments and gauge how shared decision-making supports preference-sensitive choices for patients (DF).
- Payment and delivery reform provide a unique opportunity for patients and families to be active participants in ensuring that quality reporting and provider incentives are oriented toward consumer needs, and that affordability constraints are mitigated (CM).
- There exists a tension between patient and family-centeredness and the move toward standardization in quality and safety. As we progress toward patient- and family-centered care, this tension will need to be resolved both socially and scientifically (NF).
- Patient-centered outcomes result when patients determine the questions, priorities, and focus of evidence-generating studies (SS).
- A growing body of evidence examines patient- and family-centered initiatives including: customization for patient needs, the presence of family and other caregivers, patient-driven goal setting, and the impact of built environment (SF).
- There exists a limited body of foundational evidence supporting family engagement for improved outcomes, with substantial opportunity for improvement (HM).
- The majority (70%) of patients desire online access to their data, regardless of age. The proliferation of patient data-access portals helps patients manage and coordinate their care, but is limited by barriers to interoperability (LM).
- The timing of communicating information (during visits vs. before visits) can impact the level of patient knowledge and amplify the patient voice in patient-physician interactions (JF).

Collaborative activities for consideration

- Development of a conceptual framework that embodies use of tools to enable the the full integration of patient, family, caregiver, and clinician into decision-making.
- A discussion paper on the integration of social media and online health communities with health care delivery in order to bridge informal networks of patients supporting health system and care culture transformation.
- A consensus checklist and dissemination project to support caregivers and family members' visitation rights and involvement of the patient care experience.
- A discussion paper on disparities in the use of health IT, and how this impacts health literacy and decision-making.
- A framework for holistic measurement: under the guidance of the *Vital Signs* core measures set, proposing methodologies to support the integration of social data and social determinants into electronic health records.
- A discussion paper that explores strategies, tools, and best practices for improving clinician education for patient engagement.
- A discussion paper that considers clinician satisfaction and clinician engagement, including how disagreements between patients and clinicians impact health decisions and outcomes.

Meeting participants

Mary D. Naylor (UPenn); William D. Novelli (Georgetown); Cindy Brach (AHRQ); Kristin L. Carman (AIR); Preeta Chidambaran (HRSA); Brownsyne Tucker Edmonds (National Academy of Medicine); Hala Durrah (Advocate); Nancy Foster (AHA); Floyd J. Fowler (IMDF); Susan Frampton (Planetree); Dominick Frosch (Moore); Linda Harris (HHS); Elizabeth Hoffer (GW); Lynda Honberg (Family Voices); Noelene K. Jeffers (AANM); Beverley H. Johnson (IPFCC); Tina Johnson (AANM); Andrea Borondy Kitts (Advocate); Anthony Knettel (AAHC); Marty Kohn (Sentrian); Selina McLaughlin (VCU); Susan Mende (RWJF); Tara Montgomery (Consumer Reports); (CMS) Lana Moriarty (ONC); Helene Moriarty (Villanova & UPenn); Caitlin Morris (Families USA); Alonzo Plough (RWJF); Joyce Pulcini (AAN); N. Lee Rucker, MSPH (Enhance Value); Robert Saunders (NQF); Juliette Schlucter (NYU); Sue Sheridan (PCORI); Scott Shipman (AAMC); Richard Singerman (TrustnetMD); Cheryl Sullivan (AAN); Elizabeth Thompson (C-Change); Manasi Tirodkar (NCQA); Megan M. Tschudy (AAP); Connie Ulrich (UPenn); William Vaughan (CUE); Blaine Warkentine (Vimty); Thomas A. Workman (AIR).



## THE LEADERSHIP CONSORTIUM FOR VALUE & SCIENCE-DRIVEN HEALTH CARE

<b>CHAIR</b> Mark B. McClellan The Brookings Institution	Paul Hudson AstraZeneca	Richard Platt Harvard Medical School	Debra B. Whitman AARP
<b>MEMBERS</b> Raymond J. Baxter Kaiser Permanente	Brent C. James Intermountain Healthcare	Richard J. Pollack American Hospital Association	<i>Ex-Officio</i> Richard Kronick AHRQ
Paul Bleicher Optum Labs	Craig A. Jones Vermont Blueprint for Health	Michael Rosenblatt Merck & Company	Thomas Freiden Chesley Richards CDC
David Blumenthal The Commonwealth Fund	Gary Kaplan Virginia Mason Health System	John W. Rowe Columbia University	Jonathan Woodson Department of Defense
Susan DeVore Premier, Inc.	Darrell G. Kirch AAMC	Leonard D. Schaeffer USC	Karen DeSalvo DHHS
Judith Faulkner Epic	Richard C. Larson MIT	Joe Selby PCORI	David Shulkin Carolyn M. Clancy VA
David Feinberg Geisinger Health System	Peter Long Blue Shield of CA Foundation	Mark D. Smith CA HealthCare Foundation	Stephen Ostroff Peter Lurie FDA
Joseph Fifer Healthcare Financial Management Assoc.	James L. Madara AMA	Harrison Spencer ASPPH	James Macrae HRSA
Patricia Gabow Former Denver Health	Mary D. Naylor UPenn	Jennifer Taubert Johnson & Johnson	Francis Collins Kathy Hudson NIH
Atul Gawande Harvard School of Public Health	William D. Novelli Georgetown University	Marta Tellado Consumers Union	
James Heywood PatientsLikeMe	Harold Paz Aetna	David Torchiana Partners HealthCare System	
	Jonathan B. Perlin Hospital Corporation of America	Reed V. Tuckson TucksonHealthConnections	

## CARE CULTURE & DECISION-MAKING INNOVATION COLLABORATIVE

### *Organizations Participating*

American Academy of Nursing	C.S. Mott Children's Hospital	Kaiser Permanente	Research!America
American Academy of Pediatrics	Dana-Farber Cancer Institute	Lown Institute	Robert Wood Johnson Foundation
American Coll. of Clinical Pharmacy	Dartmouth Center for Health Care	Mayo Clinic	Sanofi
American College of Nurse-Midwives	Delivery Science	Nat'l Assoc. of Comm. Health Cent.	Schwartz Center
American Hospital Association	Dell Children's Medical Center	National Business Group on Health	Sentrian
American Institutes for Research	Duke University	National Cancer Institute	Trustnet MD
American Medical Association	Emory University	Nat'l Comm. on Quality Assurance	University Hospitals
American Nurses Association	Family Voices	National Quality Forum	University of North Carolina
Anne Arundel Medical Center	Georgetown University (C-TAC)	Nemours Health System	University of Pennsylvania
Assoc. of Academic Health Centers	George Washington University	Northwestern University	University of Washington
Assoc. of American Medical Colleges	Georgia Regents Medical Center	NYU Langone Medical Center	Vidant Health System
Asthma & Allergy Found. of America	Gordon and Betty Moore Foundation	Oregon Health & Science University	Vimty
Beryl Institute	Health Policy Partners	Partnership for Patients	Virginia Commonwealth University
Blue Shield of California Foundation	Healthwise	PCORI	Federal agencies
Boston Children's Hospital	Informed Med. Decisions Foundation	PatientsLikeMe	U.S. Dep't of HHS
Braintree Rehabilitation Hospital	Institute for Healthcare Improvement	PFCC Partners	- AHRQ
Cincinnati Children's Hospital	Institute for P&F-Centered Care	Planetree	- HRSA
Consumer Reports	Johns Hopkins Health System	Qorvis MSL Group	
Consumers United for EBH	Josiah Macy, Jr. Foundation	RAND Corporation	

**Distribution to colleagues is encouraged. Additional information at: [www.nam.edu/leadershipconsortium](http://www.nam.edu/leadershipconsortium).**