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 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 Chidambaram (HRSA); Bowsyene Tucker Edmonds (National Academy of Medicine); Haia Durrah (Advocate); Nancy Foster (AHA); Floyd J. Fowler (IMDF); Susan Frampton (Planetree); Dominick Frosch (Moore); Linda Harris (HHS); Elizabeth Hoffler (GW); Lynda Honberg (Family Voices); Noelleke K. Jeffers (AANM); Beverley H. Johnson (IPFCC); Tina Johnson (AANM); Andrea Borondy Kitts (Advocate); Anthony Kneitel (AACH); 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 Va); William Vaughn (CUE); Blaine Warkentine (Vimty); Thomas A. Workman (AIR).
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  - Healthcare Financial Management Assoc.
- Patricia Gabow
  - Former Denver Health
- Atul Gawande
  - Harvard School of Public Health
- James Heywood
  - PatientsLikeMe

**Organizations Participating**

- American Academy of Nursing
- American Academy of Pediatrics
- American Coll. of Clinical Pharmacy
- American College of Nurse-Midwives
- American Hospital Association
- American Institutes for Research
- American Medical Association
- American Nurses Association
- Anne Arundel Medical Center
- Assoc. of Academic Health Centers
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- Asthma & Allergy Found. of America
- Beryl Institute
- Blue Shield of California Foundation
- Boston Children’s Hospital
- Braintree Rehabilitation Hospital
- Cincinnati Children’s Hospital
- Consumer Reports
- Consumers United for EBH

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- Marta Tellado: Consumers Union
- Francis Collins: NIH
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- David Torchiana: Partners HealthCare System
- James Macrae: Geisinger
- Jonathan B. Perlin: Hospital Corporation of America
- Reed V. Tuckson: Tuckson HealthConnections

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