

NAM PATIENT & FAMILY LEADERSHIP NETWORK

Winter 2017 Update

Colleagues: We are pleased to reach out with updates on the NAM Patient and Family Leadership Network (PFLN). The PFLN operates under the auspices of the Care Culture & Decision-Making Innovation Collaborative (CCDmIC) of the National Academy of Medicine (NAM) Leadership Consortium for a Value and Science-Driven Health System. The PFLN is a virtual Network that engages the nation's patients and families in serving as effective leaders and advisors to the NAM and others to achieve better culture, better care, better value, and better health for all in a healthcare system that continuously learns and improves.

NEW PFLN WEBSITE LAUNCHED

We are pleased to announce that we have launched a [PFLN page](#) on the NAM website. The initial launch includes the *Resource Compendium* and other resources, video testimonials, other NAM content of interest to patient and family leaders, and a mechanism to join the network. Please be in touch with your suggestions on what would be most useful to support your work in advancing patient and family engaged care, and please share the link with your networks: nam.edu/PFLN

NAM MEETINGS OF INTEREST TO NETWORK PARTICIPANTS

- **Models of Care for High-Need Patients: Workshop 3** – focus: advancing approaches, policies, and tools to enhance the spread of successful models of care delivery (co-sponsor: Peterson Center on Healthcare; October 21, 2016; [summary](#))
- **Optimizing Strategies for Clinical Decision Support Meeting** – focus: to explore and discuss opportunities and practical strategies for improving clinical decision support practices and adoption (co-sponsor: Office of the National Coordinator; October 27, 2016; [summary](#))
- **Clinical Effectiveness Research Innovation Collaborative** – focus: the characteristics and operationalization of open science. (November 3, 2016; [summary](#))
- **Digital Learning Collaborative** – focus: the potential, and rate limiting steps, of clinicians serving as partners and leaders in realizing the digital learning community. (December 1, 2016; [summary](#))
- **Care Culture and Decision-Making Innovation Collaborative** – focus: consideration of a guiding framework for a culture of patient and family engaged care. (December 7, 2016; [summary](#))
- **NAM Action Collaborative on Clinician Well-Being and Resilience** – focus: planning meeting to determine focus areas and a possible set of activities to: improve baseline understanding across organizations of challenges to clinician well-being; raise visibility of clinician stress and burnout, and; find evidence-based, multidisciplinary solutions to reverse these trends, leading to improvements in patient care by caring for the caregiver. (January 6, 2017; [website and listserv signup](#))

NAM COLLABORATIVE PROJECTS INVOLVING NETWORK ISSUES

Collaborative projects: 1) identify issues of common interest and marshal needed leadership; 2) develop tools and networks needed for progress; and 3) develop joint leadership possibilities through individually-authored *Perspectives* papers:

- **Paper:** *Harnessing Evidence and Experience to Change Culture: A Guiding Framework for Patient and Family Engaged Care*. Released on January 31, 2017, this paper presents a framework for patient and family engaged care (PFEC), along with the associated evidence supporting each element of the model. The discussion paper 1) reviews the process for developing the framework; 2) describes the elements of the framework and the associated foundational evidence; 3) positions the framework as a valuable tool for accelerating widespread adoption of patient and family engagement principles and practices; and 4) identifies specific next steps and opportunities for building on this initial work in order to promote a more systematic and sustained effort to build the evidence base for PFEC and to promote alignment of existing PFEC activities. ([Paper](#))
- **Guiding Framework for PFEC:** The discussion at the December 7th CCDmIC Meeting centered on how to advance the framework as a tool to promote effective partnerships among health system executives and patient and family leaders to create a culture of PFEC. We are interested in your feedback on the framework, and your ideas to promote the framework as a tool. ([Framework](#))
- **Resource Compendium:** With the creation and publication of the Guiding Framework for Patient and Family Engaged Care and feedback at the CCDmIC meeting, NAM will be convening an editorial council to participate on the next iteration of the *Resource Compendium for Patient & Family Health Care Leadership*. Please contact Michelle Johnston-Fleece to indicate your interest in participating on this project.

ENGAGING WITH THE PFLN

We envision the work of the PFLN to be done in virtual form, with meetings and teleconferences planned based on specific project needs. We enthusiastically invite your engagement and any input for the activities underway or with topics for potential future activities.

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THE LEARNING HEALTH SYSTEM SERIES

CARE CULTURE AND DECISION-MAKING INNOVATION COLLABORATIVE

Participating Organizations

AARP	C.S. Mott Children's Hospital	Kaiser Permanente	Robert Wood Johnson Foundation
American Academy of Nursing	Dana-Farber Cancer Institute	Lown Institute	Schwartz Ctr for Compassionate
Amer. Acad. of Physician Assistants	Dartmouth Center for Health Care	Mayo Clinic	Healthcare
American Coll of Clin Pharmacy	Delivery Science	Nat'l Assoc of Comm Health Ctrs	Sentrian
American Coll of Nurse-Midwives	Dell Children's Medical Center	National Business Group on Health	University Hospitals
American Hospital Association	Duke University	Nat'l Comm. on Quality Assurance	University of North Carolina
American Institutes for Research	Emory University	National Governors Association	University of Pennsylvania
American Medical Association	Family Voices	National Partnership for Women &	University of Washington
American Nurses Association	Georgetown University	Families	Vidant Health System
Assoc. of Academic Health Centers	George Washington University	National Quality Forum	Virginia Commonwealth University
Assoc. of American Med. Colleges	Georgia Regents Medical Center	Nemours Health System	
Asthma & Allergy Fdtn of America	Gordon and Betty Moore Fdtn.	Northwestern University	Federal agencies:
Beryl Institute	Health Dialog	NYU Langone Medical Center	U.S. Dep't of HHS
Blue Shield of California Fdtn	Healthwise	Oregon Health & Science Univ	- Centers for Medicare & Medicaid
Boston Children's Hospital	Henry J. Kaiser Family Fdtn	PCORI	Services
Braintree Rehabilitation Hospital	Health Policy Partners	Ptnt-Centered Primary Care Collab	- AHRQ
C-Change	Informed Med. Decisions Fdtn	PatientsLikeMe	- HRSA
Cincinnati Children's Hospital	Inst for Healthcare Improvement	PFCCpartners	U.S. Dep't of VA
Coalition to Transform Adv. Care	Inst for Ptnt & Fam-Centered Care	Planetree	NIH
Consumer Union	Johns Hopkins Health System	RAND Corporation	-National Cancer Institute
Consumers United for EBH	Josiah Macy, Jr. Foundation	Research!America	

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

Chair	Darrell G. Kirch	Peter J. Pronovost	Ex-Officio
Mark B. McClellan	AAMC	Johns Hopkins Medicine	AHRQ
Duke University			Sharon Arnold
Members	Richard E. Kuntz	Murray N. Ross	CDC
David Blumenthal	Medtronic	Kaiser Permanente	Anne Schuchat
The Commonwealth Fund	Peter Long	John W. Rowe	Chesley Richards
	Blue Shield of California	Columbia University	
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Joseph F. Fifer	Mary D. Naylor	Joe Selby	VA
Healthcare Financial Mgmt Assn	University of Pennsylvania	PCORI	David Shulkin
Patricia A. Gabow	William D. Novelli	Mark D. Smith	Carolyn M. Clancy
Former, Denver Health	Georgetown; C-TAC	Former, CA HealthCare	FDA
Atul Gawande	Sally Okun	Foundation	Stephen Ostroff
Brigham and Women's Hospital	PatientsLikeMe	UCSF	HRSA
Julie L. Gerberding	Harold Paz	Jennifer Taubert	James Macrae
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IBM	HCA, Inc.	Consumers Union	Michael Lauer
Brent C. James	Richard Platt	Reed V. Tuckson	
Intermountain Healthcare	Harvard Medical School	Tuckson Health Connections	
Gary Kaplan	Richard J. Pollack	Debra B. Whitman	
Virginia Mason Health System	AHA	AARP	
Gregory F. Keenan		Leadership in Transition	
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