

## NAM PATIENT & FAMILY LEADERSHIP NETWORK

Fall 2016 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 goal of the PFLN is to grow the leadership of patient and family advisory councils and related groups as a force to build the effectiveness of patients, families and the public as full partners in healthcare decisions, continuous improvement initiatives, and achieving better value and better health.

### STAFF INTRODUCTION: EMMA FINE, BA, SENIOR PROGRAM ASSISTANT

We are pleased to welcome Emma Fine to the NAM staff as a Senior Program Assistant. Prior to joining NAM, Emma worked for a state-run health insurance company in Colorado, and completed an internship with the U.S. Department of Health and Human Services in the Office of the Assistant Secretary for Preparedness and Response. Emma graduated from the University of California, Berkeley in 2016 where she earned her BA in Public Health with a minor in Public Policy. While in college, she was an active member of The Suitcase Clinic, a student-run organization created to provide health and medical services to the homeless population in Berkeley. Emma also worked as an intern through the Berkeley Health Services Program where she taught nutrition and fiscal responsibility to previously incarcerated men and women in Oakland, CA. Emma plans to pursue a graduate degree in the field of public health and looks forward to working with the PFLN.

### MEETINGS RECENTLY CONVENED BY NAM

- **Vital Directions for Health and Health Care: A National Conversation** – focus: policy opportunities identified in the discussion paper series *Vital Directions in Health and Health Care*, and identify outstanding questions and explore cross-cutting opportunities for a synthesis paper to be developed to provide streamlined information and clear priorities for the incoming administration, as well as other policy makers and the public. (September 26, 2016; [website](#))
- **Value Incentives & Systems Innovation Collaborative** – focus: activities underway in the transition to population-based payment, and strategic priorities to advance progress (September 16, 2016; [summary](#))
- **Accelerating Clinical Knowledge Generation and Use: Strategic Scale and Spread** – focus: health executive leadership for development, spread and scaling of a continuously learning health system (sponsored by PCORI; September 8, 2016; [summary](#))
- **Care Culture and Decision-Making Innovation Collaborative** – focus: strategic priorities in advancing the evidence base for patient- and family-engaged care (May 2016; [summary](#))

### COLLABORATIVE PROJECTS FOR NETWORK PARTICIPANT CONSIDERATION

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*.** Presents a framework for patient and family engaged care (PFEC), along with the associated evidence supporting each element of the model. The discussion paper will 1) review the process for developing the framework; 2) describe the elements of the framework and the associated foundational evidence; 3) position the framework as a valuable tool for accelerating widespread adoption of patient and family engagement principles and practices; and 4) identify 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. (in progress)
- **Guiding Framework for PFEC:** At the December 7<sup>th</sup> CCDmIC Meeting, we will seek suggestions to advance the guiding framework for patient and family engaged care presented in the above discussion paper. Specifically, we will discuss 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. The conversation will inform future Collaborative activities and the next iteration of the *Resource Compendium for Patient & Family Health Care Leadership*. We will be in touch with information about next steps and will solicit your expertise to inform our activities.
- **PFLN Community:** We invite your suggestions as we develop a PFLN page on the NAM website. The initial launch of the PFLN site will include the *Resource Compendium* and other resources, video testimonials and other NAM content of interest to patient and family leaders. Please be in touch with your suggestions on what would be most useful to support your work in advancing patient and family engaged care.

### STAYING ENGAGED WITH 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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Senior Program Officer

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**J. Michael McGinnis, MD, MA, MPP**

Executive Director, Leadership Consortium for a Value and Science-Driven Health System

Leonard D. Schaeffer Executive Officer, National Academy of Medicine



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

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

<b>Chair</b>	Gary Kaplan	Peter J. Pronovost	<b>Ex-Officio</b>
Mark B. McClellan	Virginia Mason Health System	Johns Hopkins Medicine	AHRQ
Duke University			Andrew B. Bindman
<b>Members</b>	Gregory F. Keenan	Murray N. Ross	CDC
David Blumenthal	AstraZeneca	Kaiser Permanente	Thomas Frieden
The Commonwealth Fund	Darrell G. Kirch	John W. Rowe	Chesley Richards
	AAMC	Columbia University	
Paul Chew	Richard E. Kuntz	Craig E. Samitt	CMS
Sanofi US	Medtronic	Anthem, Inc.	Andy Slavitt
			Patrick Conway
Susan DeVore	Peter Long	Lewis G. Sandy	DoD
Premier, Inc.	Blue Shield of California Foundation	United Health Group, Inc	Karen Guice
Judith Faulkner	James L. Madara	Leonard D. Schaeffer	DHHS
Epic Systems	AMA	USC	Karen DeSalvo
David Feinberg	Mark E. Miller	Joe Selby	VA
Geisinger Health System	MedPAC	PCORI	David Shulkin
Joseph F. Fifer	Mary D. Naylor	Mark D. Smith	Carolyn M. Clancy
Healthcare Financial Mgmt Assn	University of Pennsylvania	Former, CA HealthCare Foundation	FDA
Patricia A. Gabow	William D. Novelli	UCSF	Robert Califf
Former, Denver Health	Georgetown; C-TAC	Harrison Spencer	HRSA
Atul Gawande	Harold Paz	ASPPH	James Macrae
Brigham and Women’s Hospital	Aetna	Jennifer Taubert	NIH
Julie L. Gerberding	Jonathan B. Perlin	Johnson & Johnson	Francis Collins
Merck & Co., Inc.	HCA, Inc.	Marta Tellado	Kathy Hudson
Paul Grundy	Richard Platt	Consumers Union	
IBM	Harvard Medical School	Reed V. Tuckson	
James Heywood	Richard J. Pollack	Tuckson Health Connections	
PatientsLikeMe	AHA	Debra B. Whitman	
Brent C. James		AARP	
Intermountain Healthcare			