

NAM PATIENT & FAMILY LEADERSHIP NETWORK

Summer 2018 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.

NAM MEETINGS OF INTEREST TO NETWORK PARTICIPANTS

- **Procuring Digital Interoperability for Health Care**—focus: driving healthcare interoperability through collaborative procurement strategies (January 30, 2018; [event page](#)).
- **Better Care for High-Need Patients Webinar Series**—focus: to advance insights and perspectives on how to better manage the care of the high-need patient population (February 16, 2018 - April 25, 2018; [summary](#))
- **Building the Evidence Base for Improving Health Care Symposium**—focus: contributions of health services research (HSR) to effectiveness and efficiency in health and health care (February 26 & 27, 2018; [event page](#))
- **Care Culture and Decision-Making Innovation Collaborative Meeting**—focus: community health needs assessments as a means to activate communities in co-creating agendas to promote health and well-being. (May 17, 2018; [summary](#))
- **Evidence and the Individual Patient: Understanding Heterogeneous Treatment Effects Meeting**—focus: inherent limitations of using group data to guide treatment decisions for individuals (May 31, 2018; [event page](#))
- **Clinical Effectiveness Research Innovation Collaborative Meeting**—focus: establishing a shared vision for generating stakeholder support and demand for data sharing, linkage, and use for a continuously learning health system (June 11, 2018)
- **Digital Learning Collaborative Meeting**—focus: patient ownership of health data in a learning health system (June 28, 2018; [event page](#))

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:

- **Community Health Needs Assessments Principles & Practices: An NAM Working Group** – an *ad hoc* working group to explore principles to optimize the added value of community health needs assessments, share promising practices on the conduct of assessments, and identify how IRS regulations and requirements related to community benefit can offer more guidance.
- **Technologies to Enhance Person, Family, & Community Activation: An NAM Working Group** – an *ad hoc* working group comprised of leadership from key stakeholder sectors to identify, prioritize, and advise on key issues related to the potential of technologies to make care more patient-centered, accessible and convenient for patients, while enhancing the quality of medical decisions. The working group has identified three topics for further exploration in NAM discussion papers.
- **Patient and Family Engaged Care: Shifting Culture and Policies Improve Health and Reduce Disparities** – building on an NAM *Perspectives Harnessing Evidence and Experience to Change Culture: A Guiding Framework for Patient and Family Engaged Care* and discussions at CCDmIC meetings, a group of key thought leaders will assess issues and explore the culture change elements necessary to meaningfully engage patients, families and communities to co-create health equity and reduce health and health care disparities.
- **Hospital and Health System Leadership Incentives to Improve Health and Reduce Disparities** – An expert discussion paper, in collaboration with the American Hospital Association, will explore trends in executive compensation of hospital and health system leaders for successful reduction of health disparities and meeting population health goals.

ENGAGING WITH THE PFLN

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. Visit the website at nam.edu/PFLN for more information on activities of interest to PFLN participants.

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THE LEARNING HEALTH SYSTEM SERIES

CARE CULTURE AND DECISION-MAKING INNOVATION COLLABORATIVE

Participating Organizations

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

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

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Georges Benjamin	Medtronic	Anthem, Inc.	Brett Giroir
American Public Health Association	Peter Long	Lewis G. Sandy	VA
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The Commonwealth Fund	James L. Madara	Leonard D. Schaeffer	FDA
Susan DeVore	AMA	USC	Scott Gottlieb
Premier, Inc.	Mark E. Miller	Joe Selby	HRSA
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Julie L. Gerberding	Aetna	AARP	
Merck & Co, Inc.	Jonathan B. Perlin	Ex-Officio	
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