



NAM PATIENT & FAMILY LEADERSHIP NETWORK

Winter 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

- Leadership Consortium Members Meeting—focus: a virtual health data trust: a core utility for continuous health learning. (September 14, 2017; summary)
Digital Learning Collaborative—focus: artificial intelligence and the future of continuous health learning and improvement. (November 30, 2017; summary)
Care Culture and Decision-Making Innovation Collaborative—focus: integration of health care and social services to meet the goals and needs of individuals coping with complex care needs. (December 7, 2017; summary)
NAM Action Collaborative on Clinician Well-Being and Resilience—focus: establishing clinician well-being as a national priority. (December 15, 2017; event page)
Value and Systems Innovation Collaborative—focus: a roadmap for moving from fee-for-service to fee-for-value and population health. (December 18, 2017; summary)
Clinical Effectiveness Research Innovation Collaborative—focus: oversight and consent practices for learning activities embedded in health systems, practices, and health plans that aim to provide evidence for care improvement. (January 25, 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:

- In progress: Hospital and Health System Leadership Incentives to Improve Health & Reduce Disparities (in partnership with the American Hospital Association): The NAM is partnering with the AHA to survey its membership to understand the state of play on existing policies and incentives that are in place both at the health system, Board of Directors, and C-suite level to promote population health, disparities reduction and health equity. Findings from the survey will be presented to stakeholders in multiple venues (e.g., AHA Annual Meeting and Leadership Summit; Association for Community Health Improvement National Conference; NAM Patient & Family Leadership Network and Executive Leadership Network) for feedback. Findings and learnings from the listening sessions will be presented in an NAM discussion paper.
In progress: Enhancement of A Guiding Framework for Patient and Family Engaged Care to 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.
Regulatory supports to promote equity. Explore how IRS regulations and requirements related to community health needs assessments can offer more guidance and principles to optimize the added value of the assessments.
Telehealth and related technology. Develop a standing workgroup to facilitate collaboration for accelerating progress in development and application of technologies that facilitate direct patient, family, and community engagement in health and healthcare.
Person, family and community activation for better care, better value and better health. Develop an NAM initiative to support activation of individuals, families, and communities as effective health and health care change agents by addressing three key areas: access to the evidence base to guide strategies; collaboration to apply evidence; and cultures and policies that are supportive and facilitative of their engagement.
Advancement of patient and family engaged care. Develop common PFEC action and research agenda with a crosswalk of PFEC standards and measures and determine ways to digest the framework into messages for various stakeholders.
Assessment of community values. Using Vital Signs framework, explore metrics for assessing community values and community engagement.
Improved networking for innovations. Assess landscape of proven community engagement models and explore opportunities for better networking so information transfer about successful models is accelerated.

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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