



PATIENT & FAMILY LEADERSHIP NETWORK

An activity of the National Academy of Medicine's Care Culture and Decision-making Innovation Collaborative

Activity: The Patient & Family Leadership Network supports ongoing communication, collaboration, and synergy among patient and family thought leaders to advance their equal and full engagement across the healthcare continuum: as equal and effective partners in care decisions, at the community and organizational level via continuous improvement initiatives, and at the policy level to promote better care, better value and better health for all.

Compelling aim: *Engaged patients and citizens, better culture, better care, better health, and lower costs.* This will be accomplished by stewarding the capacity and effectiveness of patient and family thought leaders, marshaling and sharing the evidence base on their impact, and developing strategies for their involvement as full partners in health care improvement.

Issue: Involving patients and families for better informed decisions has been shown to enhance agreement on treatment plans, boost patient experience, improve health outcomes, and lower costs. Engaged patients are also more likely to consider ongoing learning and improvement a feature of standard care, and expect that their clinical data will contribute to that progress. The range of patient roles spans from being a passive “recipient” of care, fully delegating care decisions elsewhere, to being an active, fully engaged member of the care team, to full participants in the health institution’s improvement activities, and, even further, as partners and leaders in improving and implementing the evidence on effective health care. Yet involvement is hardly the norm, and the experience of activated patients varies by provider, by decision, and by system. Numerous strategies and approaches aim to encourage patients to be more involved in not only managing their own health, but participating as well in healthcare improvement initiatives, research, the development of patient-reported outcome measures and policy development. Helping meet the aims of such engagement requires a carefully considered strategy linking the experience and energies of patient and family thought leadership across the healthcare continuum.

Approach: Building on insights gleaned from preliminary assessments and meetings —e.g., *Partnering with Patients* and *Building the Patient and Family Advisory Leadership Network for Better Care*—the National Academy of Medicine (NAM) is partnering with interested stakeholder organizations and patient and family thought leaders to nurture the development of the necessary capacity for effective patient and family engagement across the healthcare continuum. The PFLN will be engaged to advise, inform and steward various collaborative activities, which will include ongoing communication and other potential projects, e.g., developing evidence on best practices; reports and reference materials; participant stories, examples, and lessons learned; video testimonials; participant contact information; real-time experience; implementation tools; meeting, training, and funding opportunities; and polls. The result will be a vibrant virtual network of patient and family thought leaders that serves as a springboard for the nation’s patients and families in serving as effective leaders and results in health care that continuously learns and improves.

Related NAM work: *Harnessing Evidence and Experience to Change Culture: A Guiding Framework for Patient and Family Engaged Care* (2017), *Vital Directions for Health and Health Care* (2016), *Resource Compendium for Patient & Family Health Care Leadership* (2015), *Patients and Health Care Teams Forging Effective Partnerships* (2014), *Shared Decision-Making Strategies for Best Care: Patient Decision Aids* (2014), *Health Literacy and Numeracy - Workshop Summary* (2014), *Social Networking Sites and the Continuously Learning Health System: A Survey* (2014), *Making the Case for Continuous Learning from Routinely Collected Data* (2013), *Best Care at Lower Cost* (2012), *Core Principles and Values of Effective Team-Based Health Care* (2012), *Demanding Value from Our Health Care: Motivating Patient Action to Reduce Waste in Health Care* (2012), *Challenges at the Intersection of Team-Based and Patient-Centered Health Care* (*JAMA*, 2012), and the *Learning Health System Series* (2006-2011).

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The National Academy of Sciences

The National Academy of Sciences (NAS) is a non-governmental organization comprised of the nation's leading scientists. Chartered by Congress and President Abraham Lincoln in 1863, NAS is called upon to serve as the adviser to the Government and to the nation on matters of scientific research and policy. Presidential Executive Orders have defined the special relationship of the Academy to Government and cited its unique capacity to marshal scientific expertise of the highest caliber for independent and objective science policy advice. As matters of health and medicine became more compelling and specialized, the Institute of Medicine (IOM) was established under the charter of the NAS in 1970 as the nation's adviser on health, health science, and health policy. Like its sister organizations, the National Academy of Sciences and the National Academy of Engineering, IOM members (65 each year) are elected by the current membership and drawn from nation's leading authorities in medicine, health, the life sciences, and related policies.

The National Academy of Medicine

The National Academies, including the NAM and the IOM, work outside the framework of government, although often at the request of Congress or government agencies to ensure that objective and scientifically informed analysis and independent guidance are brought to bear on the most difficult and challenging health issues facing the nation. Working together in consensus committees, public forums, and collaborative efforts, invited experts carry out the technical and policy studies commissioned to produce advice on compelling health challenges, meetings and symposia convened on matters of widespread interest, and projects to catalyze recommended action. Each year, more than 2000 national experts—members and nonmembers—volunteer their time, knowledge and expertise to advance the nation's health through the NAM and the IOM

The National Academy of Engineering

Founded in 1964, the National Academy of Engineering (NAE) is a private, independent, nonprofit institution that provides engineering leadership in service to the nation. The mission of the National Academy of Engineering is to advance the well-being of the nation by promoting a vibrant engineering profession and by marshalling the expertise and insights of eminent engineers to provide independent advice to the federal government on matters involving engineering and technology. The NAE has more than 2,000 peer-elected members and foreign associates, senior professionals in business, academia, and government who are among the world's most accomplished engineers. They provide the leadership and expertise for numerous projects focused on the relationships between engineering, technology, and the quality of life.

Rights and responsibilities under the Congressional Charter

The three National Academies have a long tradition of providing national advice and leadership, which rests on their ability to convene experts and other diverse stakeholders charged with considering important issues of science, engineering, and health policy in an objective, independent, and trusted environment that assures rigorous analysis. Because the National Academies provide the Federal Government with a unique service, activities are accorded a special status by charter and the implementing Executive Orders of the President. Specifically, *"when a department or agency of the executive branch of the Government determines that the Academy, because of its unique qualifications, is the only source that can provide the measure of expertise, independence, objectivity, and audience acceptance necessary to meet the department's or agency's program requirements, acquisition of services by the Academy may be obtained on a noncompetitive basis if otherwise in accordance with applicable law and regulations."* (Executive Order 12832)