



Patient and Caregiver Engagement Advisory Group

BACKGROUND

NQF has expanded its efforts to meaningfully engage patients and caregivers in its work with the convening of a Patient and Caregiver Engagement Advisory Group. The patient and caregiver voice is vital to the multistakeholder consensus process, to grounding and shaping the landscape of quality measurement, and to improving healthcare quality and outcomes. NQF seeks to implement practices, processes, and infrastructure to:

- Mitigate barriers to participation and create a welcoming experience for patients and caregivers collaborating with NQF;
- Prepare patients and caregivers for a successful experience by providing training and support that enable meaningful participation;
- Ground NQF work and outputs in real experiences to ensure that patient and caregiver voices are heard; and
- Foster a convening culture and environment that support and promote patient participation.

GROUP CHARGE

The NQF Patient and Caregiver Engagement Advisory Group provides strategic input and direction on engaging patients and caregivers in shaping NQF processes, programs, products, and deliverables. This group advises NQF on matters related to recruitment, education, and retention of patient/caregiver representatives in NQF's Consensus Development Process (CDP), Measure Applications Partnership (MAP), and measurement science projects.

Specifically, the group is charged with the following activities:

- Help guide the strategic priorities and activities for engaging patients in the CDP, MAP, and measurement science efforts.
- Provide input and feedback on strategies to recruit patients onto NQF committees.
- Assist in recruitment and retention activities.
- Provide strategic direction to overcome barriers to participation and prepare patients and caregivers to participate successfully in the technical aspects of the committee and project work.
- Provide feedback on NQF endorsement criteria and process changes.

COMPOSITION

NQF convened this 15-member group to represent the diverse experiences of patients and caregivers and bring expertise and experience in patient advocacy, patient engagement, patient education on relevant healthcare topics, and many other talents. Members were selected based on their experience and commitment to patient engagement in healthcare quality issues and

sharing this experience and knowledge to support NQF efforts to engage patients in our work.

NQF defines patients, caregivers, and representatives as the following:

- **Patients:** Persons who have direct experience, either currently or in the past, with an illness or injury and whose primary representation is the patient perspective.¹
- **Caregiver:** A family member or other unpaid caregiver with a significant personal relationship with a patient (as defined above), who provides a broad range of assistance for the person receiving care, and represents this perspective.²
- **Patient and caregiver representatives:** Members of advocacy organizations or other organizations that represent patients or caregivers and their interests. These representatives may include organizations that represent populations of patients or caregivers and/or patients with certain diseases or conditions.

ADVISORY GROUP MEMBERS

David Andrews, PhD

Patient-Advisor, Retired
Ailken, South Carolina

David Andrews is a former college professor of psychology (cognitive neuroscience) with extensive teaching and experience in organizational development and assessment. He has in the last 14-plus years served as a patient advisor with Medical College of Georgia (now Augusta University) and a variety of regional and national organizations.

David's primary focus as patient advisor has been on improving the meaningful and effective engagement of patients and caregivers in their own care and in the work of healthcare organizations.

Amy Basken, MS

Director of Programs, Pediatric Congenital Heart Association
Madison, Wisconsin

Amy Basken is a mother of a child with congenital heart disease (CHD). She has in the last 13 years led CHD advocacy efforts for many of the largest national congenital heart disease organizations, coalitions, and consortiums. In her role as co-founder and director of programs at the Pediatric Congenital Heart Association, she works with patients, families, providers, and policymakers to educate and advocate around critical issues such as federal research funding and the importance of life-long care. Amy has become a nationally recognized expert on patient engagement and the importance of data transparency and public reporting.

Amy has a master of science degree from the University of Wisconsin – Madison, graduating in 1996. She worked for 10 years as a clinical speech pathologist prior to the birth of her third child

¹ Adapted from PCORI definition of patient: <https://www.pcori.org/engagement/what-we-mean-engagement/pcoris-stakeholders>

² Adapted from the Family Caregiver Alliance definition of family (informal) caregiver: <https://www.caregiver.org/definitions-0>

with congenital heart disease.

When she is not working to empower others, Amy is busy managing an active household that includes her husband and three teenage children. In any spare time, you will find Amy singing, knitting, or escaping on a long walk with the dog.

Carol Cronin

Founder, Informed Patient Institute
Washington, District of Columbia

Carol Cronin founded the Informed Patient Institute in 2007. Prior to this, she worked as a consultant and advisor to nonprofit organizations, foundations, and government agencies including the California Endowment, AARP, and Atlantic Philanthropies.

Carol served as director of the Center for Beneficiary Services at the Health Care Financing Administration (HCFA – now CMS) from 1998-2000. She was responsible for the launch of <http://www.medicare.gov> and other consumer-oriented activities. Prior to HCFA, she was senior vice president for Health Pages, a New York City-based consumer health information website and worked in leadership positions at the Washington (now National) Business Group on Health.

She currently serves on the Boards of the National Quality Forum, the Physician Consortium for Performance Improvement (PCPI), the Patients' View Institute, and the Citizen Advocacy Center. She also sits on the Vision for the Future Commission looking at continuing board certification and the Johns Hopkins Hospital Patient and Family Advisory Council and patient safety committee.

Carol is currently working to establish a collaborative to work on end-of-life/serious illness care in Maryland. She holds an AB degree from Smith College and two master's degrees in social work and gerontology from the University of Southern California.

Jill Harrison, PhD

Director of Research, Planetree International
Debry, Connecticut

Dr. Jill Harrison currently serves as the director of research for Planetree International, a nonprofit organization dedicated to person-centered healthcare. In addition to this role, she also serves on the Patient-Centered Outcomes Research Institute (PCORI) Advisory Panel for Patient Engagement through 2021. Her prior work includes serving on a scientific advisory panel convened by The National Academy of Medicine to evaluate the strength of the evidence for patient and family engaged care.

Martin Hatlie

President and CEO, Project Patient Care
Chicago, Illinois

Martin Hatlie is president and CEO for Project Patient Care, a Chicago-based safety and quality improvement coalition dedicated to using the patient voice to improve care. He also serves as co-director of the MedStar Institute for Quality & Safety, which integrates open and honest communication strategies, patient and family engagement, research, education and high reliability organization methods into quality and safety improvement. He is active in federal health system transformation work as a consultant on projects funded by Centers for Medicare

and Medicaid Services, Agency for Healthcare Research and Quality, and the Patient Centered Outcomes Research Institute.

Loriana Hernandez-Aldama

Journalist, Patient Advocate, Leukemia Survivor, ArmorUp for LIFE
Chester Spring, Pennsylvania

Loriana Hernandez-Aldama is an Emmy award-winning journalist with more than 20 years of on-air television experience nationally and locally as an anchor and medical/health/fitness reporter. During her cancer diagnosis and fierce one-year battle she uncovered the biggest story of her career when doctors told her the more fit she was, the more aggressively they could treat her and the better her chances of survival. She founded the nonprofit, ArmorUp for LIFE with the core message of PREhabilitation, meeting the medicine halfway, showing up fit for the fight and becoming your own HERO.

Loriana now advocates for those affected by cancer and sheds light on the gaps in treatment to improve patient outcomes and compliance. Her work has been recognized in Cancer Today magazine, in Cancer.net and she has successfully completed the AACR Scientist-Survivor Advocacy Program.

Clarissa Hoover, MPH

Project Director, Family Voices
Albuquerque, New Mexico

Clarissa Hoover is currently project director at Family Voices where she is involved in development and validation of a ground-breaking measure of family-centered care. In her capacity she promotes research partnerships with diverse and underserved communities of children and youth with special healthcare needs at the Children and Youth with Special Healthcare Needs Research Network (CYSHCNet) and Lifecourse Interventions Research Network (LCI-RN).

She earned her master's in public health with a focus on patient and family engagement and training in community-based participatory research methods in 2013. She was the lead author of *A Framework for Assessing Family Engagement in Systems Change* and is currently involved in development of the Family Engagement in Systems Assessment Tool.

Clarissa has lived experience as a family caregiver to a child with special healthcare needs and brings a background in anthropology and data management to her public health role, which is reflected in her three-part approach to any issue: understand the cultural diversity; understand the lived experience; and understand the data.

Stephen Hoy

Chief Operating Officer, PFCCpartners
Long Beach, California

Stephen Hoy is COO of PFCCpartners and has multiple chronic conditions which include mitochondrial disease and scoliosis; this, however, does not deter him from pursuing an active outdoor lifestyle. With PFCCpartners, he aids in building infrastructure and strategy for authentic and sustainable PFE in hospitals, health systems, research teams, and measure development processes.

Stephen also serves as an advisor at his local critical access hospital; patient partner on AIR's patient-centered measurement project team, and CMS Patient Family Engagement Champions Group as well as a member on the NQF Patient Experience and Function Standing Committee.

Patricia Kelmar, JD

Senior Policy Advisor, New Jersey Health Care Quality Institute
Princeton, New Jersey

Patricia Kelmar has 15 years plus of experience in patient safety and consumer advocacy, strategy development, analyzing legislation/regulation, and developing quality initiatives. She is closely connected to patient organizations and patient activists through her former position at AARP and the Consumer Reports' Safe Patient Project (now called Patient Safety Action Network).

During her tenure at AARP New Jersey, she actively engaged patients and AARP members in an extensive three-year campaign to win public reporting of infections, adverse events, and patient safety indicators in New Jersey. During this time Patricia realized how difficult it can be for consumers to find and use quality measures and worked to educate AARP members and the public through workshops and various earned media strategies.

Patricia has dedicated her career to empowering consumers in healthcare, financial security, and patient safety. She has served on boards of patient organizations in New Hampshire and Connecticut, and volunteers for families in need as Trustee for Catholic Charities, offering social services in Hartford.

Barbara Lewis

Joan's Family Bill of Rights
Sherman Oaks, California

Barbara started her career writing for national publications, including *The Wall Street Journal* and, more recently, *Modern Healthcare*, and the *British Medical Journal*. She launched a marketing company, which she helmed for two and a half decades, during which time she received an MBA from the UCLA Anderson School of Management, where she taught for two years. Since her sister's death, she has been working with organizations to embed the patient voice and enhance the patient experience, which includes helping to improve quality.

Joan Maxwell

Patient Advisor, John Muir Health; Senior Advisor, MakerSights
Orinda, California

Joan Maxwell is a senior advisor for MakerSights, a tech start-up in the Bay Area. She has 40-plus years of experience in the fashion industry, working for retailers and brands such as Vera Bradley where she as VP of merchandising.

Her passion in patient experience came when she was a patient at John Muir Hospital in Walnut Creek. She works at the national level to encourage the voice of the patient in healthcare discussions and serves on the Advisory Board of PFCC Partners and the Cal Hospital Compare Technical Advisory Board. Joan has since its inception in 2015 served as an advisor on the Patient & Family Advisory Committee at John Muir Health.

Gwen Mayes, JD, MMSc

Patient Story Coach/ Writer, Self-Employed
Annapolis, Maryland

Gwen Mayes is a lawyer who having lived with cardiac disease for more than 30-years is well versed in regulatory language through the lens of a patient. Gwen holds a master's in medical science in advanced respiratory care and has worked as a physician assistant for a heart transplant program. Her career spans the field of patient advocacy, government affairs, and regulatory for medical device and pharma industries.

Gwen is a frequent speaker and writer on patient advocacy. She once served as EVP of Public Policy for National Patient Advocate Foundation during enactment of Affordable Care Act and is well versed on principles for increasing patient input, e.g., PCORI, PDUFA, and now 21st Cures.

Laura Townsend

Louise H. Batz Patient Safety Foundation
San Antonio, Texas

Laura Batz Townsend and her family created the Louise H. Batz Patient Safety Foundation in 2009 after Laura's mother lost her life to a preventable medical error. They turned heartbreak into the promise of improved safety for hospital patients. Laura grew up in the medical community, with five physicians in her family. She worked for 13 years in the sports marketing and grant management field. That family medical background combined with Laura's development skills equipped her family to create the Batz Foundation in hopes that others could avoid the family tragedy they experienced upon the untimely loss of their mother.

Janice Tufte

Patient partner, Hassanah Consulting
Seattle, Washington

Janice Tufte is a Medicaid expansion recipient living with multiple chronic conditions: eye, hearing, musculoskeletal, digestive diseases that require critical care. As a patient partner, she has helped develop six projects addressing the social determinants of health and equity in the greater Puget Sound area. The projects which include Emergency Muslim Resource Guides and WarmforWinter focus on alleviating poverty challenges through small community involved projects bringing awareness with simple opportunities.

Janice lead the GHRI/KPWHRI research grant in 2012 which focused on health systems improvement research work. She has also served as a part-time co-investigator on the KPWHRI LINCC project as well as on seven PCORI-funded projects providing the patient public perspective and voice to the projects. She currently serves as a PCORI ambassador and is expected to share about the importance of quality improvement through measurements and guidelines in an upcoming PCORI ambassador webinar.

Daniel van Leeuwen, RN MPH

Retired
Arlington, Massachusetts

Daniel van Leeuwen has been a nurse for 45 years and is living with multiple sclerosis. Daniel has been a care partner for several family members on their end-of-life journeys; an informaticist; QI

leader; mentor to leaders and advocates, and a patient/caregiver activist. Daniel spent over 25 years as director/VP of quality management with responsibility for patient and provider engagement and quality measurement. He currently serves on the steering committee of AHRQ's Patient-Centered Clinical Decision Support (PCCDS) Learning Network, and he is a reviewer for PCORI research funding applications and a technical expert for the CMS-funded Supporting Efficiency and Innovation in the Process of Developing CMS Quality Measures. Daniel is also participating in the National Academy of Medicine's Digital Learning Collaborative on Patient Ownership of Data and Data Sharing.

Daniel considered empowering patients and caregivers to engage in their medical decisions as his skill and passion. He believes engaging lay people in measurement and measurement development is critical to sustaining meaningful evaluation of health outcomes.