



Multistakeholder Input on Priority Setting for Health Care Performance Measurement: Getting to Measures that Matter

Person-Centered Care and Outcomes Committee Roster

Uma Kotagal, MBBS, MSc (Co-Chair)

Cincinnati Children's Hospital Medical Center, Cincinnati, OH

Sally Okun, RN (Co-Chair)

PatientsLikeMe, Cambridge, MA

Ethan Basch, MD, MSc

University of North Carolina at Chapel Hill, Chapel Hill, NC

Dave deBronkart, Jr.

Society for Participatory Medicine, Nashua, NH

Joyce Dubow, MUP

AARP, Washington, D.C.

Jennifer Eames-Huff, MPH

Consumer-Purchaser Disclosure Project, San Francisco, CA

Troy Fiesinger, MD

Memorial Family Medicine Residency, Sugar Land, TX

Christopher Forrest, MD, PhD

The Children's Hospital of Philadelphia, University of Pennsylvania, Philadelphia, PA

Lori Frank, PhD

Patient-Centered Outcomes Research Institute, Washington, D.C.

Priti Jhingran, BPharm, PhD

GlaxoSmithKline, Research Triangle Park, NC

Lisa Latts, MD, MSPH, MBA, FACP

LML Health Solutions, LLC, Denver, CO

Bruce Leff, MD

Johns Hopkins University School of Medicine, Baltimore, MD

Michael Lepore, PhD

Planetree, Atlanta, GA



Mary MacDonald, MS, BA

American Federation of Teachers, Washington, D.C.

Mary Minniti, CPHQ

Institute for Patient-and Family-Centered Care, Eugene, OR

Eugene Nelson, MPH, DSc

Dartmouth Institute for Health Policy and Clinical Practice, Lebanon, NH

Mark Nyman, MD, FACP

Mayo Clinic, Rochester, MN

Laurel Radwin, RN, PhD

Veterans Administration, Manchester, NH

Anne Walling, MD, PhD

University of California-Los Angeles, Los Angeles, CA



Person Centered Care and Outcomes Committee Biographies

Uma Kotagal, MBBS, MSc, is senior vice president for quality, safety and transformation and executive director of the James M. Anderson Center for Health Systems Excellence at Cincinnati Children's Hospital Medical Center. As director of the Anderson Center, Dr. Kotagal oversees the development of disease management teams and development and institution of evidence-based clinical practice guidelines. Dr. Kotagal was director of the neonatal intensive care units at the University Hospital and at Cincinnati Children's for several years. While practicing, Dr. Kotagal recognized that care and outcomes improvement were a system property. She completed additional training, receiving her masters of science in clinical epidemiology and clinical effectiveness from the Harvard School of Public Health, and refocused her clinical efforts on quality transformation at a systems level. She was also a visiting scholar at the Center for Risk Analysis at the Harvard School of Public Health and a visiting professor at the Tufts New England Medical Center, in the Division of Clinical Decision Making, completing further training in the field of decision and cost effectiveness analyses.

Sally Okun, RN is the Vice President for Advocacy, Policy and Patient Safety at PatientsLikeMe in Cambridge, MA. She is responsible for the company's patient advocacy initiatives; she participates and contributes to health policy discussions at the national and global level; and she is the company's liaison with government and regulatory agencies. Sally joined the company in 2008 as the manager of Health Data Integrity and Patient Safety overseeing the site's medical ontology including the curation of patient-reported health data and an ever-evolving patient vocabulary. She also developed and manages the PatientsLikeMe Drug Safety and Pharmacovigilance Platform. Prior to joining PatientsLikeMe Sally, a registered nurse, practiced as a palliative and end-of-life care specialist. In addition as an independent consultant she contributed to multiple clinical, research, and educational projects focused on palliative and end-of-life care for numerous clients including Brown University, Harvard Medical School, MA Department of Mental Health, Hospice Education Network and the Robert Wood Johnson Foundation.

Ethan Basch, MD, MSc, is an oncologist and outcomes researcher at Memorial Sloan-Kettering Cancer Center who directs a program on patient-reported outcomes, clinical informatics, comparative effectiveness and product safety evaluation. He leads the National Cancer Institute's PRO-CTCAE initiative to develop a standardized patient-centered approach to adverse event reporting in clinical trials. Dr. Basch is a member of the PCORI Methodology Committee and chairs the Patient-Centeredness Workgroup. He is immediate past Chair of the American Society of Clinical Oncology Clinical Practice Guidelines Committee, member of the Comparative Effectiveness Research Task Force and liaison to the Quality of Care Committee.

Dave deBronkart, widely known as e-Patient Dave, is a cancer patient and blogger who, in 2009, became a noted activist for healthcare transformation through participatory medicine and personal health data rights. In 2007 he was diagnosed with metastatic kidney cancer. He ultimately beat the disease by accessing online resources, seeking information about his disease on the web and sharing



access to his medical record. Dave is now a nationally and internationally known spokesperson for the e-Patient movement and shares his experience as an empowered, engaged patient leader.

Joyce Dubow, MUP, is a member of the NQF Board of Directors. She served two terms on the Consensus Standards Approval Committee and was its inaugural chair. She co-chaired the Patient-reported Outcomes technical committee and represents AARP on the Coordinating Committee of the Measure Application Partnership and the National Priorities Partnership. She has served on numerous NQF steering and ad hoc committees including: the Steering Committee and Workshop on National Voluntary Consensus Standards for Hospital Care, the Steering Committee for Additional Priority Areas for Hospitals; the HCAHPS Review Committee; the Steering Committee for Standardizing Ambulatory Care Performance Measures; the Steering Committee on National Consensus Standards for the Reporting of Healthcare-associated Infections Data; the Priority and Goal Setting Steering Committee on Efficiency; and the Ad Hoc Committee on Improving NQF's Consensus Development Process. She represents AARP on the Consumer Council.

Jennifer Eames Huff, MPH, is Director for the Consumer-Purchaser Disclosure Project. The Consumer-Purchaser Disclosure Project is a group of leading employer, consumer, and labor organizations improving health care quality and affordability by advancing public reporting of provider performance information so it can be used for improvement, consumer choice, and payment. Ms. Huff brings over seventeen years' experience working in the arena of health care performance measurement to the project. Prior to joining PBGH Ms. Huff was a Health Economist at Genentech, where she contributed to the development and commercialization of products by overseeing patient reported outcomes and providing economic assessments. Before that, she was a Program Officer at the California HealthCare Foundation (CHCF). While at CHCF she managed a portfolio of projects related to patient safety, health disparities and the public reporting of provider performance. When she left the Picker Institute in Boston, Ms. Huff was Director of Client Services. At the Picker Institute, she helped clients measure patients' experience with care and use the information for improvement, public reporting, and financial rewards. Her clients included hospital associations, health systems and employer coalitions located throughout the US. She also has held quality management positions at health systems in New England. Ms. Huff earned a BA with Honors from Wellesley College and an MPH in Health Policy and Management from University of California at Berkeley.

Troy Fiesinger, MD, currently serves on the faculty of the Memorial Family Medicine Residency Program in Sugar Land, Texas and holds an adjunct assistant professorship at the Texas A&M University. He graduated from Baylor College of Medicine in 1996 and completed his residency at East Carolina University in 1999. He then worked for Scott and White Healthcare in Waco, Texas. While there he helped lead quality improvement efforts as the Regional Clinic Director for Quality and Safety. He then served as the medical director for a federally-qualified health center and residency faculty in Conroe, Texas. He has participated in performance measure workgroups for the AMA's Physician Consortium for Performance Improvement, the American Board of Medical Specialties, and the National Quality Forum. He previously served on the AAFP's Commission on Quality and Practice.



Christopher Forrest, MD, PhD, is a Professor of Pediatrics and Health Care Management at the University of Pennsylvania and Children's Hospital of Philadelphia (CHOP). He leads a research center that focuses on the measurement of health across the life course and development of a national pediatric learning health system. He provides leadership for a federally funded Pediatric Quality Measures Program Center of Excellence, a national program in pediatric learning health systems (which are dedicated to advancing the health of children through research, quality improvement, and informatics), the National Children's Study health measurement network, and the NIH's Patient Reported Outcome Measurement Information System's (PROMIS) Executive Committee and serves on the Steering Committee for the National Children Study's Health Measurement Network.

Lori Frank, PhD, has worked as a PRO researcher for over 15 years. At PCORI Dr. Frank's work as Director, Engagement Research focuses on the patient perspective on comparative effectiveness research. As Executive Director of the Center for Health Outcomes Research at United BioSource she led multiple PRO development and psychometric evaluation studies, and initiated and led the Cognition Initiative, now part of the Critical Path Institute PRO Consortium. Her published work includes both qualitative and quantitative studies of PROs. Dr. Frank serves on the Memory Screening Advisory Board of the Alzheimer's Foundation of America and has also served on the Center for Trauma and the Community of Georgetown University Department of Psychiatry, engaging patients and clinicians from local clinics for the under-served in the research process.

Priti Jhingran, BPharm, PhD, is Senior Director in US Health Outcomes at GlaxoSmithKline. Dr. Jhingran is an Institutional Council member of ISPOR since 2007 and participated in various workstreams. In addition, Dr. Jhingran was the founding Co-Director of the Patient Reported Outcomes (PRO) Consortium in 2009 for 2 years. Dr. Jhingran has been a lead/contributing researcher for many PROs that have become mainstream assessment tools in various diseases areas. These include Asthma Control test, Migraine Specific Quality of Life Questionnaire, COPD Assessment Tool, and many more. Most recently, Dr. Jhingran was appointed on the PCORI Advisory Board focusing on Diagnosis, Treatment, and Prevention.

Lisa Latts, MD, MSPH, MBA, FACP, is the Principle for LML Health Solutions, a healthcare quality and delivery system transformation consulting firm. Prior to this, Dr. Latts was a Vice President with WellPoint. In her 14 years with WellPoint, Dr Latts led WellPoint's innovative quality strategy, which included initiatives to measure and improve the health of WellPoint's members and communities, measure and promote health equity, patient safety and many others. She was instrumental in developing many of WellPoint's delivery system reform initiatives such as Patient-Centered Medical Home, Centers of Excellence, and Medical Tourism. She is a nationally-known leader and has served on many national committees including with NCQA and NQF.

Bruce Leff, MD, is Professor of Medicine at the Johns Hopkins University Schools of Medicine and Public Health. He is an active clinician in the ambulatory, home, nursing home, rehabilitation, and hospital settings. His research focuses on innovative models of patient-centered care and the care of people with multiple chronic conditions. He was a co-author of the white paper for NQF on performance



measurement for people with multiple chronic conditions. He is currently working on the development of quality measures for people cared for in medical house calls practices. He is a member of the MAP post-acute and long-term care committee.

Michael Lepore, PhD, is Planetree's Director of Research and an adjunct Assistant Professor in Health Services, Policy & Practice at Brown University. A sociologist by training, Dr. Lepore transitioned to health services research after working as a nursing assistant in long-term care. His research examines patient-centered care, and healthcare quality, access, and equity. With Planetree, a network of healthcare organizations committed to patient-centered care, Dr. Lepore's work focuses on implementing and evaluating patient-centered care across the spectrum of healthcare settings internationally. A recognized thought leader, Dr. Lepore was an invited speaker at numerous venues in 2013, including the NQF annual conference.

Mary MacDonald, MS, BA, is Director, Healthcare division of American Federation of Teachers. Previously worked for national AFL-CIO and served as faculty on the extension division of Cornell University's School of Industrial and Labor Relations. Currently Chair of the NQF Consumer Council. Served on the Board of the Maryland Health Care Foundation. U.S. Labor representative for development of ILO standard on substance abuse in the workplace, Geneva, Switzerland. U.S. representative and panelist at United Nations Conference on Drugs in the Workplace, Seville, Spain. M.S. in Industrial and Labor Relations from Cornell University.

Mary Minniti, is a Certified Professional in Healthcare Quality. She has worked in quality improvement and community organizing for more than 30 years. She joined the Institute for Patient- and Family-Centered Care in 2011 as a Program and Resource Specialist and provides onsite training and technical assistance to health care organizations, develops publications and resources, and serves as faculty for the Institute's seminars and conferences. Her work with the Institute began in 2003 as guest faculty for an intensive training seminar.

Eugene Nelson, MPH, DSc, is Professor of Community and Family Medicine at The Dartmouth Institute for Health Policy and Clinical Practice, Dartmouth Medical School; Director, Population Health Measurement Program, The Dartmouth Institute; Director, Population Health and Measurement, Dartmouth-Hitchcock Medical Center. Dr. Nelson is a national leader in health care improvement and the development and application of measures of quality, system performance, health outcomes, value, and patient and customer perceptions. His work to develop the "clinical value compass" and "whole system measures" to assess health care system performance has made him a well-recognized quality and value measurement expert. He is the recipient of The Joint Commission's Ernest A. Codman award for his work on outcomes measurement in health care. Dr. Nelson, who has been a pioneer in bringing modern quality improvement thinking into the mainstream of health care, helped launch the Institute for Healthcare Improvement and served as a founding Board Member.

Mark Nyman, MD, FACP, has been involved with Quality Improvement activities over the last 18 years. Involvement has included guideline development and implementation at Mayo Clinic and with



the Institute for Clinical Systems Improvement; six years of service - Board of Directors for Minnesota Community Measurement (MNCM); and current membership - MNCM Measurement Advisory Reporting Committee. He is the chair of Mayo Clinic's Patient Profile Subcommittee, a new committee charged with standardizing the capture of data (answers to clinical questions obtained in a discrete electronic format) from patients including Patient Reported Outcomes, and includes standardization of the content across the entire practice.

Laurel Radwin, RN, PhD, after conducting qualitative research of nurses' and patients' perceptions of coordinated, individualized, responsive and proficient care, and completing performance measurement coursework, Laurel Radwin, RN, PhD, developed and tested patient-reported measures. One scale is included in the AHRQ's Atlas of Care Coordination Measures and has been translated into 15 languages. Dr. Radwin is currently studying care coordination for Veterans who transition among settings, and has comprehensively reviewed measures of coordination from clinicians' and patients' perspectives. Furthermore, Dr. Radwin's scales have been shown to be sensitive to diverse patients' perceptions of care, and her contribution to disparities research has been formally recognized by Howard University.

Anne Walling, MD, PhD, is a palliative care physician and health services researcher who has focused on measuring and improving the quality of care for patients with life-limiting illness including those with hope for cure. She has worked with RAND's ACOVE (Assessing Care of Vulnerable Elders) and ASSIST (Assessing Symptoms Side Effects and Indicators of Supportive Treatment) quality measurement projects. Her research with quality measures has led in part to the National Quality Forum Endorsement for RAND end of life quality indicators.