Patient-Centered Outcomes Research Institute

Transforming Patient-Centered Research: Building Partnerships and Promising Models

Workshop Leaders

The *Transforming Patient-Centered Research: Building Partnerships and Promising Models* workshop is being led by PCORI's Director of Patient Engagement, Susan Sheridan. She is joined by a group of dedicated and passionate facilitators who will guide you through this workshop's activities. Their pictures and brief background information is provided below, so that you can get to know them better and recognize a familiar face when you arrive.

Workshop Facilitators

Joe Selby, MD, MPH

Executive Director
Patient-Centered Outcomes Research Institute

Joe Selby is the first Executive Director of the Patient-Centered Outcomes Research Institute (PCORI). A family physician, clinical epidemiologist and health services researcher, Joe has more than 35 years of experience in patient care, research and administration. He is responsible for identifying strategic issues and opportunities for PCORI and implementing and administering programs authorized by the PCORI Board of Governors. Joe joined PCORI from Kaiser Permanente, Northern California, where he was Director of the Division of Research for 13 years and oversaw a department of more than 50 investigators and 500 research staff working on more than 250 ongoing studies. He was with Kaiser Permanente for 27 years. An accomplished researcher, Joe has authored more than 200 peer-reviewed articles and continues to conduct research, primarily in the areas of diabetes outcomes and quality improvement. His publications cover a spectrum of topics, including effectiveness studies of colorectal cancer screening strategies; treatment effectiveness, population management and disparities in diabetes mellitus; primary care delivery and quality measurement.

Anne Beal, MD, MPH

Chief Operating Officer
Patient-Centered Outcomes Research Institute

Anne C. Beal is chief operating officer of the Patient-Centered Outcomes Research Institute. A pediatrician and public health specialist, she has devoted her career to providing access to high-quality health care through the delivery of health care services, teaching, research, public health, and philanthropy. As PCORI's first COO, Beal is responsible for ensuring PCORI develops the structure and capacity needed to carry out its mission as the nation's largest research institute focused on patient-centered outcomes research. Anne joins PCORI from the Aetna Foundation, the independent charitable and philanthropic arm of Aetna Inc. As president, she led the foundations work on improving health care in the U.S., particularly for vulnerable patient groups. is also the author of The Black Parenting Book: Caring for Our Children in the First Five Years. Dr. Beal has been a pediatric commentator and medical correspondent for Essence magazine, The American Baby Show, ABC News, and NBC News. Anne holds a B.A. from Brown University, an M.D. from Cornell University Medical College, and an M.P.H. from Columbia University. She completed her internship, residency, and National Research Service Award fellowship at Albert Einstein College of Medicine/Montefiore Medical Center in the Bronx.

Susan E. Sheridan, MIM, MBA

Director of Patient Engagement
Patient-Centered Outcomes Research Institute

Sue became involved in patient safety after her family experienced two serious medical system failures. Her husband, Pat, died in 2002 after his diagnosis of spinal cancer failed to be communicated. Their son, Cal, suffered brain damage called kernicterus five days after his birth in 1995 when his neonatal jaundice was untreated. She is Co-Founder and Past President of Parents of Infants and Children with Kernicterus, which works in partnership with private and public health agencies to eradicate kernicterus. In 2004, Sue was asked to lead the World Health Organization's Patients for Patient Safety initiative, a program under the WHO Patient Safety Program who embraces the collective wisdom of the patient, patient empowerment and patient centered care. She speaks frequently on patient safety and legal reform at national and international events and was named to *Modern Healthcare*'s list of Top 25 Women in Healthcare as well as *Modern Healthcare's* 100 Most Powerful People in Healthcare. Sue received her BA from Albion College and her MIM and MBA from Thunderbird School of Global Management.

Rachael Fleurence, PhD

Scientist
Patient-Centered Outcomes Research Institute

Rachael Fleurence is a scientist at the Patient-Centered Outcomes Research Institute (PCORI). She is responsible for PCORI's research prioritization process in collaboration with PCORI staff, the Board of Governors, the Methodology Committee and patients and stakeholders. Rachael is an expert in systematic reviews and evidence synthesis and over the past several years has focused on using these methods in comparative effectiveness research. She served as chair of the International Society of Pharmacoeconomics and Outcomes Research's (ISPOR's) Health Policy Special Interest Group, Value Based Health Care, during the 2011-12 and co-chaired the 2011 ISPOR issue panel review committee for the Society's sixteenth annual meeting. She is an associate editor of the journal Health Outcomes Research in Medicine. She is also coediting a volume on comparative effectiveness for an upcoming handbook on health services research. Rachael received a doctorate in health sciences and a master's degree in health economics from the University of York, in the United Kingdom, and a master's degree in business management from Ecole Supérieure des Sciences Economiques et Commerciales in Paris.

Lori Frank, PhD

Director, Engagement Research
Patient-Centered Outcomes Research Institute

Lori Frank is the Director of Engagement Research at the Patient-Centered Outcomes Research Institute (PCORI). Her current research focus is on bringing the patient perspective to comparative effectiveness research to enhance the meaningfulness of outcomes and to improve decision-making by healthcare consumers and providers. Prior to joining PCORI, Lori worked as a Director in Health Outcomes and Pharmacoeconomics at MedImmune, LLC with a focus on oncology, and prior to that she spent over 13 years with MEDTAP International/ United BioSource Corporation, where she was Senior Research Leader and Executive Director of the Center for Health Outcomes Research. Her research on patient-based health outcomes assessment centers on psychiatric disorders. Her other work addresses psychological, ethical, and legal aspects of memory screening and medical treatment decision making by older adult patients. She serves on the Memory Screening Advisory Board of the Alzheimer's Foundation of America, bringing the patient perspective to this work to maximize patient autonomy and optimize patient and caregiver care decision-making.

Martin J. Hatlie, JD

Chief Executive Officer
Project Patient Care

Martin Hatlie is CEO of Project Patient Care whose mission is to mobilize the diverse healthcare stakeholders in metropolitan Chicago to provide the best possible care to every patient every time, by eliminating preventable harm and implementing systemic change to ensure consistent excellence. Drawing on experience as a civil rights attorney, malpractice defense litigator, lobbyist and coalition-builder, Martin is active in both public and organizational policy development on patient safety, litigation reform and patient safety issues. He works extensively with consumers and organizations to foster the cultural paradigm shift necessary to support a patient-centered, systems-based approach to the delivery of healthcare services. Martin is co-editor of the *Patient Safety Handbook*, a leading textbook in the field of patient safety, and he has authored numerous articles addressing patient safety and medical liability issues. He has organized and facilitated patient safety workshops for the World Health Organization across the globe.

Susan Hildebrandt, MA

Director, Stakeholder Engagement
Patient-Centered Outcomes Research Institute

Susan Hildebrandt is the Director of Stakeholder Engagement for the Patient-Centered Outcomes Research Institute (PCORI). She is responsible for leading PCORI's engagement with clinicians, policymakers, professional audiences and the broader health care community. Hildebrandt is an experienced government relations professional with longstanding knowledge of patient-centered research. She has more than 25 years of communications, public policy and health care advocacy experience. Most recently, Hildebrandt was Assistant Director for Government Relations at the American Academy of Family Physicians (AAFP). At the AAFP, Hildebrandt worked on policy issues including comparative effectiveness research, health care reform, delivery system reform, research, and health information technology, among others. She earned her bachelor's degree with distinction in Political Science and German from the University of Michigan, and a master's degree at the University of Pennsylvania.

Greg Martin

Deputy Director, Stakeholder Engagement
Patient-Centered Outcomes Research Institute

Greg Martin is the Deputy Director of Stakeholder Engagement for the Patient-Centered Outcomes Research Institute (PCORI). He is responsible for leading PCORI's state- and local-level engagement with clinicians, policymakers, professional audiences and the broader health care community. An experienced state health policy and state government affairs professional, Greg previously served the American Academy of Family Physicians (AAFP) and National Conference of State Legislatures (NCSL). In his prior role, Greg was responsible for leading AAFP's governmental advocacy assistance to its state and territorial chapters, including research on issues such as health reform implementation, Medicaid and the patient-centered medical home. With NCSL, Greg served as staff to the Forum for State Health Policy Leadership, providing analysis and technical assistance to legislators and legislative staff on a range of issues, including Medicaid, CHIP and health information technology. Greg received his bachelor's degree in political science from Mary Washington College in Fredericksburg, Virginia.

Eric Meade

Vice President and Senior Futurist
Institute for Alternative Futures

Eric Meade's recent work includes developing scenarios of primary care in 2025 for the Kresge Foundation and of vulnerability in the U.S. in 2030 for the Robert Wood Johnson Foundation. His work in the future of poverty and development includes a recent article in *World Future Review* entitled "What if we loved the poor?", developing a "pro-poor scenario toolkit" for the Rockefeller Foundation, and meeting with Grameen Bank founder and Nobel Peace laureate Muhammad Yunus to discuss how futures methods can be used to identify emerging opportunities to promote international development. Eric has worked previously as a business executive in Asia, where he set up the China sourcing operation of U.S. toy company Melissa & Doug, Inc., and as a nuclear submarine officer in the U.S. Navy. Eric has an MBA from INSEAD and a Bachelor's degree in history from the University of Virginia. He is also a certified practitioner of the Myers-Briggs Type Indicator (MBTI). He serves on the Board of Directors of Counterpart International, a non-profit dedicated to sustainable global development, and is a member of the World Future Society and the Association of Professional Futurists.

Jonathan Peck

President and Senior Futurist
Institute for Alternative Futures

Jonathan Peck provides a wide range of research, consulting, speaking, meeting design and facilitation services. A certified Myers-Briggs Type Indicator (MBTI) practitioner, Jonathan has integrated psychological patterns and insights into his facilitation of vision, mission, and strategic processes for corporations, organizations and government agencies. He led IAF's *2019: Health Care That Works for All* project, which has sketched out a visionary outcome of ten years of U.S. healthcare reform. His work on the future of health spans scientific, economic, political and social changes that can be addressed with an understanding of complex systems dynamics. Jonathan has co-authored two books and written numerous articles which have been published in *Business and Health*, *Pharmaceutical Executive*, *Food & Drug Law Review*, *Clinical Cancer Research*, *The Monitor*, *Futures Research Quarterly* and many other publications. Jonathan received his Master's degree at the Futures Studies Program in the Political Science Department of the University of Hawaii.

Workshop Presenters

The workshop will benefit from an impressive group of expert presenters, listed below, who will share their experiences in creating models for patient-centered research.

Vinod (Vinny) K. Bhutani

Professor of Pediatrics
Stanford University School of Medicine and Lucile Packard Children's Hospital

Vinod (Vinny) K. Bhutani is the Professor of Pediatrics at Stanford University School of Medicine and Lucile Packard Children's Hospital and leads the Global Prevention of Kernicterus Network. His global heath-societal research interests to prevent jaundice-related newborn brain damage through systems-approach, biotechnologies, biodesign of affordable medical devices and chemoprevention as well as development of affordable and sustainable high quality strategies and policies were pioneered through transdisciplinary research including partnership with families who children sustained Kernicterus.

Janice Bowie, PhD, MPH

Associate Professor, Department of Health, Behavior and Society
Johns Hopkins Bloomberg School of Public Health

Janice Bowie, PhD, MPH is an Associate Professor in the Department of Health, Behavior and Society (Johns Hopkins Bloomberg School of Public Health, JHBSPH) and the Hopkins Center for Health Disparities Solutions. Janice also is a contributing investigator to the Center for Mental Health Services in Pediatric Primary Care at the JHBPSH, chairs the community advisory committee, and is part of the faculty for the training component of the Operations Core, with a focus on recruiting minority students and faculty to the Center's activities. Her research objectives include examining psychosocial and behavioral factors that influence minority and women's health, exploring the implications of religion and spirituality for various health outcomes and identifying and assessing approaches that lead to the success and sustainability of community-based interventions in highest-risk communities. In 2011, Janice and Mrs. Lee Bone were awarded the Tom Bruce Award, established by the Community-Based Public Health (CBPH) Caucus of the American Public Health Association (APHA) and presented annually to an individual who exemplifies leadership in community-based public health.

Childlene Brooks

Program Planner
Brookletts Place – Talbots Senior Center

Talbot County, Maryland native Childlene Brooks is employed by Upper Shore Aging Inc. at Brookletts Place-Talbot Senior Center as a program planner. Prior to this position, she had retired from the state of Maryland, Talbot County Health Department, as the agency procurement coordinator. She began working as an outreach worker in the local Breast and Cervical Cancer Screening Program in September 1993. She lives in Wittman and has a daughter, Paulette, and a grandson, Quentin. Her list of activities as a volunteer is lengthy. Childlene is a volunteer on the Outreach Committee of New St. John's U.M. Church in Wittman; Talbot County American Cancer Society Leadership Council; member of the Board of Directors of the Bay Hundred Community Volunteers; president, Family and Friends of Asbury and Green Chappel Inc.; and serves in many other roles for community organizations. Currently, she is serving as the Daughter Ruler for Bright With Pride Temple #1375 - Easton, and has served in several other organizations and capacities within the Elks.

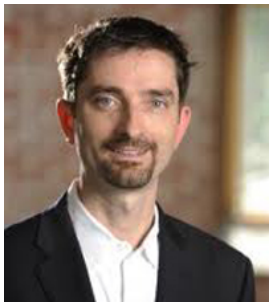
Maret Felzien

Associate Professor of Reading
Northeastern Junior College

Maret Felzien, a native to northeastern Colorado, works as the Associate Professor of Reading at the local 2-year college, Northeastern Junior College, and has a high school aged daughter. Maret and her husband, Ned, became involved in Community Based Participatory Research with the Community Advisory Council for the High Plain Research Network in 2003. Additionally, Maret serves as Co- Chair of the PACT Council--Partnership of Academicians and Communities for Translation--a component of Colorado's Clinical and Translational Sciences Institute at the University of Colorado Anschutz Medical School. She also serves as faculty for the Institute for Patient and Family Centered Care. Maret has a Bachelor's from Colorado State University and a Master's from University of New Mexico in Adult and Multicultural Education.

Benjamin Heywood, MBA

Founder
PatientsLikeMe.com



Benjamin Heywood has served as the president and director of PatientsLikeMe since its inception in 2004. His professional experience spans a diverse set of operational areas including successful ventures in the medical device industry, the entertainment industry, and in speculative residential real estate development. Prior to co-founding PatientsLikeMe, Ben was a Creative Executive at the film and television production company SideStreet Entertainment. While working in Hollywood, he produced an award-winning short film, Flush, and worked in both production and script development on numerous films. A highly regarded thought leader in the Health 2.0 industry, Ben is a frequent speaker at conferences and source for the news media on topics in this space. He has been quoted in New York Times Magazine, CNNMoney and numerous trade publications. Ben earned his Bachelor's degree in Mechanical Engineering from MIT and received his MBA from the UCLA Anderson Graduate School of Management.

Ned Norman

Associate Professor of Reading
Northeastern Junior College

Ned Norman is a Colorado native, born and raised in inner city Denver. He has a Bachelor of a Fine Art's degree from the School of the Art Institute of Chicago, which did little to prepare him for the life of cattle ranching and dry-land farming that he now enjoys on the windswept prairie of Northeast Colorado. He ended up in this predicament after marrying Maret Felzien and following her home to the family farm that has been in the family for four generations. Ned and his wife became involved in Community Based Practice Research (CBPR) when they joined the Community Advisory Council for the High Plains Research Network at its inception in 2003. This unforeseen adventure gives them a deeply meaningful way to impact the health of their immediate community, while also allowing them to positively influence the way the healthcare providers and researchers interact with their sparse, under-served population. When not fixing fences, Ned can be found cycling, gardening, Crossfitting, and posting photos and writings about his pastoral lifestyle on his website: www.road12.com.

Kris Schulze

Co-Founder, Executive Board Member
Parents of Infants and Children with Kernicterus

Kris Schulze is co-founder and executive board member of Parents of Infants and Children with Kernicterus, a non-profit parent-run organization partnering with the medical community to drive systemic-change into the treatment of newborn jaundice and the prevention of kernicterus. She is the mother of Justin, a 14-year old baseball-loving, straight A-student, who has severe cerebral palsy as a result of newborn jaundice and 11-year old science-loving Nathan. In her role as the Tech Connections Initiative Manager for the MN Department of Transportation, she strives to enhance communications, collaboration and innovation throughout the department through the use of technology.

Workshop Working Group

The workshop was developed with input from a multi-stakeholder Working Group to ensure it is a positive and rewarding experience for everyone involved. Their pictures and brief background information is provided below, so that you can get to know them better and recognize a familiar face when you arrive.

Ethan Basch, PhD

Practicing Medical Oncologist and Director of the Cancer Outcomes Research Program
University of North Carolina
Member, PCORI Methodology Committee

Ethan Basch is a practicing medical oncologist and Director of the Cancer Outcomes Research Program at the University of North Carolina in Chapel Hill. His own research focuses on patient-reported outcomes, clinical informatics, and comparative effectiveness. Studies by his group have determined that patient self-reporting of adverse events can improve data accuracy and comprehensiveness compared to clinician reporting. Building on this work, he leads the National Cancer Institute's PRO-CTCAE initiative to develop a standardized patient-centered approach to safety reporting in clinical trials. He serves as a member of the Methodology Committee of the Patient-Centered Outcomes Research Institute (PCORI) for which he co-chairs the Patient-Centeredness Workgroup. He also chairs the Health Outcomes Committee of the Alliance for Clinical Trials in Oncology, is a member of the Board of the International Society for Quality of Life Research, and a member of the Board of Scientific Advisors of the National Cancer Institute. The overall goal of Ethan's work is to improve our understanding of, and the quality of, patients' experiences with illness and care.

Charles "Chuck" Bell

Programs Director, External Affairs & Advocacy
Consumers Union

Charles Bell is Programs Director for Consumers Union, the nonprofit publisher of Consumer Reports magazine. Over his twenty years at Consumers Union, Charles has helped to provide consumer and policy information on nursing home quality, preventive health services, dietary supplements, Medicare HMOs, and external grievance programs, and to improve consumer services in low-income neighborhoods. Charles has written articles on health care and consumer affairs topics, which have been published in several local and national media outlets. He is co-author of "Covering the Health of Local Nursing Homes," published by the Association of Health Care Journalists and the Center for Excellence in Health Care Journalism in 2009. Charles holds a B.A. in political science from Antioch University. He studied at the Atkinson Graduate School of Management at Willamette University in Salem, OR, and is currently pursuing a master's degree in international business at the Columbia University School of International and Public Affairs.

Marc Boutin

Executive Vice President and Chief Operating Officer
National Health Council

Marc Boutin is the executive vice president and chief operating officer of the National Health Council, an organization that brings together all segments of the health care community to provide a united voice for the more than 133 million people with chronic diseases and disabilities and their family caregivers. In addition to overseeing financial management and operations at the National Health Council (NHC), Marc builds consensus among member patient advocacy organizations enabling them to speak with one voice on systemic health research and health care policy initiatives. This united effort results in legislation and regulations that address the collective needs of patients and their family caregivers. In addition, he provides guidance to patient organizations on various association issues, including corporate structure, government relations, fundraising, and outreach. Marc is a regular spokesperson before the media, Congress, and policy makers on major issues of interest to the patient community.

Perry Cohen, PhD

Public Health and Medical Research Expert

Perry Cohen is a public health and medical research expert with a background in organizational development, program evaluation, and systems planning in broad areas of health services, medical research and regulatory evaluation of innovation in medical technology. His diagnosis with Parkinson's disease in 1996 followed more than 20 years as health policy and management consultant. Ever since, he has been a national leader in advocacy for interests of Parkinson's disease (PD) patients. Perry founded the Parkinson Pipeline Project in 2002 to engage people with Parkinson's (PWP) in clinical research and to add the voice of PWP to the evaluation of new therapies. As a leader in the Working Group on Evidence Based Medicine, he has been a spokesman for all patients. Perry earned a Ph.D. and M.S. in Organizational Development and Marketing Research from MIT, Sloan School of Management; and a B.S. in Management Science and Math from Carnegie-Mellon University, Tepper School.

Richard “Dave” deBronkart

e-Patient Dave

Dave deBronkart, known online as e-Patient Dave, beat stage IV cancer in 2007 and became a blogger, keynote speaker and health policy advisor. He is today the leading spokesman for patient engagement, attending over 150 conferences and policy meetings internationally in the past two years. He serves as volunteer co-chair of the Society for Participatory Medicine. e-Patient Dave has appeared in Time, U.S. News, Wired, MIT Technology Review, and the HealthLeaders cover story “Patient of the Future.” In 2009HealthLeaders named him and his doctor to their annual list of “20 People Who Make Healthcare Better,” and in 2011 his TEDx talk (http://on.TED.com/Dave) went viral globally: volunteers have added subtitles in 25 languages. Its tagline is his appeal: “Let Patients Help.”

Sara Traigle van Geertruyden

Health Care and Welfare Policy Expert
Thorn Run Partners

Sara joined Thorn Run Partners in January 2011 as a health care and welfare policy expert with 14 years of experience. Among her greatest successes, in 2005-2006, Sara managed the Medicare Rx Education Network, a coalition of over 80 national associations brought together by a mutual goal of educating seniors about the new Part D benefit under Medicare. In 2009-2010, Sara successfully represented a Louisiana-based coalition of health care providers seeking to avoid a dramatic reduction in Medicaid payments after Hurricanes Katrina and Rita as part of the new health reform law. After being deeply involved in efforts to reauthorize the Temporary Assistance for Needy Families (T.A.N.F.) law during her tenure on Capitol Hill, Sara continues to work on issues related to the health and welfare of low income families and children. She completed her JD in law at the Catholic University Columbus School of Law in 2002.

Regina Greer-Smith, MPH, FACHE

President
Healthcare Research Associates, LLC

Regina Greer-Smith is President of Healthcare Research Associates, LLC, which focuses on design, implementation, and delivery of services and solutions to communities served by its clients. She is a board-certified healthcare executive with extensive project management experience, specializing in re-engineering healthcare system operations to achieve cost savings and operational improvement. Her commitment to patient safety also is grounded in her family's personal experience with preventable harm incurred during medical care. Regina is a Fellow at the American College of Healthcare Executives and is active in the Health Information Management System Society (HIMSS) and the National Association of Health Services Executives (NAHSE). Her commitment to communities of color has led her to her active partnership with the American Heart Association (AHA), where she has served as Ambassador, state advocacy board member, and volunteer lobbyist. Regina has been designated a Patient Safety Champion by the World Health Organization's Patients for Patient Safety Program.

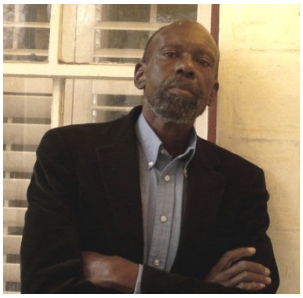
Gail Gibson Hunt

President and Chief Executive Officer
National Alliance for Caregiving
Member, PCORI Board of Governors

Gail Hunt is President and CEO of the National Alliance for Caregiving, a non-profit coalition dedicated to conducting research and developing national programs for family caregivers and the professionals who serve them. Prior to heading NAC, Gail was President of her own aging services consulting firm for 14 years. She conducted corporate eldercare research for the National Institute on Aging and the Social Security Administration, developed training for caregivers with AARP and the American Occupational Therapy Association, and designed a corporate eldercare program for EAPs with the Employee Assistance Professional Association. She was appointed by the White House to serve on the Policy Committee for the 2005 White House Conference on Aging. Gail was on the Advisory Panel on Medicare Education, is chair of the National Center on Senior Transportation, is a Commissioner of the Center for Aging Service Technology, and is Secretary of the Long-Term Quality Alliance. Additionally, Gail is on the Governing Board of the Patient-Centered Outcomes Research Institute (PCORI).

Reggie James

Director, Policy Outreach & Southwest Office
Consumers Union, the policy arm of Consumer Reports



Reggie James has spent most of his professional career as an advocate for Consumers Union, publisher of Consumer Reports. Before he was elevated to Director of the Southwest Regional Office in 1996, he engaged in legislative and regulatory advocacy on a wide range of consumer issues, including Consumer rights/access to court, environmental health/justice, auto lemon law and others. Currently, he helps maintain a list of a little more than 1 million on-line activists. Most recently, Reggie has been working with Dr. John Santa, director of Consumer Reports Rating center, on various projects relating to identifying and engaging consumer stakeholders in Effective Health Care programs. He serves on the board of the ACLU of Texas, the Consumer Federation of America and the Texas Fund for Environmental Education.

Linda K. Kenney

Executive Director and President
MITSS (Medically Induced Trauma Support Services, Inc.)

Linda founded MITSS in 2002 as the result of a personal experience with adverse medical event, when she identified the need for support services in cases of adverse events and outlined an agenda for change. Since that time, she has been a tireless activist for patient, family, and clinician rights. She has become a nationally and internationally recognized leader in the patient safety movement and speaks regularly at healthcare conferences and forums. In 2006, Linda was the first consumer graduate of the prestigious HRET/AHA Patient Leadership Fellowship. That same year, she was the recipient of the National Patient Safety Foundation's esteemed Socius Award, an annual award given in recognition of effective partnering in pursuit of patient safety. She has authored and contributed to a number of publications on topics including the emotional impact of adverse events on patients, families, and clinicians. Linda serves on the boards of the Massachusetts Coalition for the Prevention of Medical Errors, National Patient Safety Foundation and Planetree.

Angela Ostrom

Director, Federal Relations
Epilepsy Foundation

Angela has spent the last 13 years working in disability and health policy. Prior to joining the Epilepsy Foundation, she was Assistant Director of Advocacy for the National Osteoporosis Society and worked for over five years at the National Multiple Sclerosis Society as Senior Director of Public Policy & Advocacy Research. At the Foundation, Angela is responsible for federal health policy, including access to quality health care and the Medicare program. She serves as Chair of the National Health Council Government Relations Affinity Group, Co-Chair of the Health Task Force for the Consortium of Citizens with Disabilities, and as a Steering Committee Member for the Partnership to Improve Patient Care. Angela earned her Bachelor of Arts degree from The Ohio State University in 1996 and her law degree from the University of Maryland School of Law in 1999.

Kristen Sloan

Vice President
National Partnership for Women & Families

Kristen is responsible for the National Partnership for Women & Families' multi-faceted health portfolio. Prior to joining the National Partnership, Kirsten was the Director of Federal Health Issues for AARP the nation's largest consumer organization. In that role, she served as chief health lobbyist and managed a team of senior lobbyists in AARP's Government Relations Department. Kirsten and her team worked directly with the Congress and the Administration on advancing AARP's key health care priorities including Medicare, prescription drugs, long-term care, Medicaid, managed care, health insurance, and health care quality. Earlier in her career at AARP, Sloan worked as the National Coordinator for Health Issues, the Health Team Deputy Director, chief Medicare lobbyist, and as a Legislative Specialist with a special focus on the Catastrophic Coverage Act. Kirsten Sloan is a graduate of the University of Washington in Seattle, WA. She currently resides in Washington, D.C.

Kalahn Taylor-Clark, BA, MPH, PhD

Director of Health Policy
National Partnership for Women & Families

Kalahn's primary responsibilities are in shaping and implementing the policy agenda for the National Partnership's major initiative, the Campaign for Better Care. She also provides strategic policy support on a range of activities related to delivery system reform, including payment reform, quality measurement, reduction of health disparities, consumer engagement, promotion of patient-centered care delivery, and the effective use of health information technology (HIT). Prior to joining the National Partnership, Kalahn led the Patient-Centeredness and Health Equity Portfolio at the Engelberg Center for Health Care Reform at the Brookings Institution, where she currently retains an affiliation as a Visiting Scholar. This portfolio sought to advance priorities for patient-reported measurement in new delivery and payment reform models; incorporate consumer perspectives into strategic planning of new delivery reforms; focus on social determinants and population health in health care reform models; and identify innovative ways to collect and report data to measure and address health care disparities. Kahlahn received a BA in International Relations from Tufts University, an MPH from Tufts School of Medicine, and a PhD in Health Policy from Harvard University.

Mary Tinetti, PhD

Gladys Phillips Crofoot Professor of Medicine and Epidemiology
Yale School of Medicine and Chief of the Section of Geriatrics
Member, PCORI Methodology Committee

Mary Tinetti's current research focus is on clinical decision-making for older adults in the face of multiple health conditions, particularly trade-offs among health conditions and the harms and benefits of commonly recommended treatments. She has over 150 original peer reviewed publications as well as several reviews and book chapters. She is also a Viewpoint writer for JAMA. In addition to her research, Mary provides care to older adults at Yale New Haven Hospital. She is currently a member of the Methodology Committee of the Patient-reported Outcome Institute (PCORI) in which she co-chaired the Patient-Centered Workgroup (PCWG). She has received numerous awards including the Outstanding Investigator Award and the Henderson Award from the American Geriatrics Society. Mary received her undergraduate and medical degrees from the University of Michigan and completed a geriatric and clinical epidemiology fellowship at the University of Rochester following an internal medicine residency at the University of Minnesota.