



Patient and Clinician  
Engagement (PaCE)  
Preconference

November 21, 2014  
Marriot Marquis Hotel  
New York, New York



Dear NYC 2014 PaCE participant,

*Welcome!* We want to thank you for joining us for the first Patient and Clinician Engagement (PaCE) Preconference!

The PaCE Preconference is part of NAPCRG's new initiative: Engaging Patients and Providers in Patient-Centered Outcomes Research (EPPiPCORT). The purpose of EPPiPCORT is to develop a robust community of patients and primary care providers with knowledge and understanding of the unique features of patient-centered outcomes research related to primary care.

Too often, community partners in health research consist of health professionals and organizational leaders. EPPiPCORT aims to identify partners who are the "non-usual suspects" – people who are not necessarily medical or public health professionals, who are not aligned with a particular professional or personal research policy agenda, and whose local influence is defined within the context of the community versus job titles or credentials.

The objectives of the EPPiPCORT project are to:

1. Hold PaCE Preconferences to provide training for patients and primary care providers on the following topics:
  - Primary care
  - Primary care research
  - Patient-Centered Outcomes Research
  - PCORI grant review
  - Pipeline-to-proposal development and grant writing
2. Support local symposia conducted by PaCE dyads
3. Produce webinars on essential elements of primary care and patient-centered outcomes research
4. Dyad evaluation of primary care research findings at NAPCRG meetings
5. Support PaCE dyads who will submit a PCORI Pipeline-to-proposal
6. Identify, train, and support PaCE dyads to become PCORI grant reviewers

Thank you again for joining us in NYC! We are looking forward to getting to know each of you, and to our continued partnership with the PaCE dyads throughout the EPPiPCORT project.

Sincerely,

The EPPiPCORT Team

*This work was supported through a Patient-Centered Outcomes Research Institute (PCORI) Program Award (NCHR 1000-30-10-10 EA-0001)*



***NAPCRG Patient and Clinician Engagement (PaCE)  
Preconference Schedule***

**Friday, November 21, 2014**

**7:30 am – 5:00 pm**

*Marriot Marquis - Meeting Room: Chelsea/Gotham*

- 7:30-8:00am**      **Breakfast**
- 8:00-8:30 am**      **Welcome and Introductions** (*Jack Westfall, MD*)
- 8:30-9:00am**      **Patient's Perspective** (*Ned Norman*)
- 9:00-10:30am**      **Plenary Session 1:** What is primary care? (*Val Gilchrist, MD*)  
What is primary care research? (*Perry Dickinson, MD*)
- 10:30-10:45am**      **Break**
- 10:45-11:45am**      **Plenary Session 2:** Primary Care Research Advocacy (*Marci Nielsen, PhD, MPH,*  
*Facilitated by Hope Wittenberg, MA*)
- 11:45-Noon**      **Patient and Clinician Engagement in NAPCRG Annual Meeting** (*Jessica Sand, MPH*)
- Noon-1:00pm**      **Lunch and Discussion:** Patient Engagement in Canada (*Nancy Mason MacLellan,*  
*Facilitated by Rick Glazier, MD, MPH*)
- 1:00-2:00pm**      **Plenary Session 3:** PCORI 101 (*David Hickam, MD, MPH*)
- 2:00-2:15pm**      **Break**
- 2:15-3:00pm**      **Plenary Session 4:** PCORI Pipeline to Proposal (*Courtney Clyatt, MA*)
- 3:00-4:00pm**      **Plenary Session 5:** PCORI Merit Review (*Tsahai Tafari, PhD*)
- 4:00-5:00pm**      **Closing Session and Preparations** (*Jack Westfall, MD*)

**Sunday, November 23, 2014**

*Marriot Marquis*

- 1:00-2:30 pm**      **National Research Network Dyad Session** – Meeting Room: Westside Ballroom  
(*Wilson Pace, MD, and Kim Kimminau, PhD*)
- 2:30-4:30pm**      **Group Discussion & Follow-up** – Meeting room: Empire/Hudson (*Jack Westfall, MD*)

## PaCE Preconference Participants 2014

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**JOHN M. (JACK) WESTFALL, MD, MPH**  
**Chief Medical Officer, Colorado Health Cooperative Director,**  
**High Plains Research Network**  
**Professor, University of Colorado School of Medicine**

In June 2013, Dr. Westfall was named the Chief Medical Officer for the Colorado Health Cooperative (Colorado HealthOP), Colorado's first statewide nonprofit health insurance cooperative established in March 2012. Dr. Westfall will lead a statewide integrated care model and population health programs to optimize the CO-OP's clinical effectiveness.

Much of his work has also focused on determining innovative coverage options and incentives for members. Already, Jack has successfully made the case for coverage and reimbursement to practices for home blood pressure monitoring. He helped decide that the HealthOp will be the first health plan in Colorado's individual and small group markets to not exclude transgender health in their coverage policy. Under Dr. Westfall's leadership, Colorado HealthOP will build an environment that "not only provides sick care, but also supports healthy living."

Dr. Westfall is a Clinical Professor of Family Medicine at the University of Colorado School of Medicine. Since 1995, he has served as Associate Dean for Rural Health and was the Patrick and Kathleen Thompson Endowed Chair in Rural Health from 2008 to 2013. Dr. Westfall practices at the Yuma Clinic in Yuma, Colorado, the Plains Medical Center in Limon, Colorado, and for Rose Family Medicine in Denver. He is the Founder and Director of the High Plains Research Network (founded in 1997), an integrated practice-based research network of rural and frontier hospitals, clinics, and clinicians dedicated to improving medical care in rural Colorado. He has conducted research on a host of topics including cardiac care, palliative care, medical mistakes, colon cancer prevention, asthma, underinsurance, patient centered medical home, and integrated behavioral health. He also served as Director of Community Engagement for the Colorado Clinical Translational Science Institute.

Dr. Westfall was born and raised in rural eastern Colorado. He is the recipient of both the Chancellor's Diversity Award from the University of Colorado Denver and the North American Primary Care Research Group President's Award. The focus of Dr. Westfall's work is building bridges between rural communities and health care resources. Dr. Westfall is married to Dr. Audrey Yee, a neurologist, and they have two sons, Matthew and Noah.

**Research Interests**

- Rural health research
- Community engagement
- Community-based participatory research
- Women's health research
- Cardiovascular health
- Healthcare workforce and pipeline

**Previous Leadership**

- Professor, Family Medicine, University of Colorado School of Medicine
- Associate Dean of Rural Health, University of Colorado School of Medicine
- Director, High Plains Research Network (HPRN)
- Director, Colorado AHEC System, University of Colorado Denver
- Director, CCTSI Community Engagement Core
- Patrick and Kathy Thompson Endowed Chair in Rural Health



**NED NORMAN**

I am a Colorado native, born and raised in inner city Denver. I hold a Bachelor of Fine Arts degree from the School of the Art Institute of Chicago which did little to prepare me for the life of cattle ranching and dry-land farming that I now enjoy on the windswept prairie of northeast Colorado. I ended up in this predicament after marrying Maret Felzien and following her home to the family farm, which has been in the family for four generations. I have lived on our ranch outside of Sterling, Colorado for twenty years where I run a cow/calf herd of approximately ninety Angus cows and assist in the farming of winter wheat and corn.

I joined the Community Advisory Council for the High Plains Research Network (HPRN) at its inception in 2003. This unforeseen adventure gives me a deeply meaningful way to impact the health of my immediate community, while also allowing me to positively influence the way healthcare providers and researchers interact with our sparse, under-served population. More recently, HPRN’s Community Advisory Council has been also involved in the broader, national drive towards more community engagement, translation, and advocacy. The work has been not only mentally stimulating, but it has provided opportunities to travel, present at conferences, and publish papers. (Not that my cows care.)



**PERRY DICKINSON, MD**

Perry Dickinson, M.D. is a Professor in the Department of Family Medicine of the University of Colorado School of Medicine. He is Past President of the Society of Teachers of Family Medicine, the North American Primary Care Research Group, the Board of Directors of the Annals of Family Medicine, and the Council of Academic Family Medicine.

Dr. Dickinson has led multiple studies investigating primary care practice redesign, patient self-management support, and the integration of mental and behavioral health into primary care practices. He is leading the development of the Colorado Health Extension Service, a statewide effort to assist communities and primary care practices in efforts to improve health and health care.



**VALERIE GILCHRIST, MD**

Dr. Valerie Gilchrist, currently the Chair of the Department of Family Medicine at the School of Medicine and Public Health, University of Wisconsin received her medical degree with honors from the University of Toronto, in Toronto, Ontario, Canada. She attended a Fellowship in Faculty Development at the University of North Carolina-Chapel Hill 1982-1983, and the Hedwig Van Ameringen Executive Leadership in Academic Medicine (ELAM) Program 1999-2000.

She is board certified in Family Medicine and was the Chair of Family Medicine at the Northeastern Ohio Universities College of Medicine 1997-2005, and Brody School of Medicine East Carolina University 2005-2007. She has received numerous awards including: “The Leadership Award” from the North Carolina Academy of Family Physicians in 2005, “Excellence in Education” from *Ohio Magazine* in 2004, “STFM Research Paper Award” in 1999, from Northeastern Ohio Universities College of Medicine “Master Teacher Award” in 2002, “Gender Equity Award” in 1999, “Liebelt/Wheeler Award for Faculty Excellence” 1992. She received an honorary degree from the University of Pécs, Hungary in 2002 for her work helping that school develop family medicine education.

She is the co-editor of four books, one monograph, numerous book chapters, peer-reviewed publications, and grant awards. She has been a reviewer for the National Board of Medical Examiners, currently sits on a study section for AHRQ, and has been a member of several editorial boards. She is currently on the Board of Directors of the North American Primary Care Research Group, has been on the Board of Directors of the Society of Teachers in Family Medicine, The Association of Departments of Family Medicine, The Council of Academic Societies of the American Association of Medical Colleges, and the Ohio, North Carolina, and Wisconsin Academies of Family Physicians.

She maintains an active clinical practice at the Belleville Family Medical Clinic. She is married to William Scott and has three children Morgaine, Douglas, and Andrew.



**MARCI NIELSEN, PhD, MPH**  
**Chief Executive Officer, Patient Centered Primary Care Collaborative**

Marci Nielsen, PhD, MPH, joined the PCPCC as Chief Executive Officer in 2012. Prior to the PCPCC, Dr. Nielsen served as Vice Chancellor for Public Affairs and Associate Professor at the University of Kansas School of Medicine's Department of Health Policy and Management. Dr. Nielsen was appointed by then-Governor Kathleen Sebelius as first Board Chair, and subsequently became Executive Director of the Kansas Health Policy Authority (KHPA), the single state agency managing Medicaid,

the State Children's Health Insurance Program, the State Employee Health Plan, health information technology and health policy. She worked as a legislative assistant to US Senator Bob Kerrey (D-Nebraska), and later served as the health lobbyist and assistant director of legislation for the American Federation of Labor and Congress of Industrial Organizations (AFL-CIO).

She is on the Board of Directors for the American Board of Family Medicine and the Center for Health Policy Development/National Academy for State Health Policy, and is a former Board member of the Health Care Foundation of Greater Kansas City, TransformMED LLC and the Mid-America Coalition on Health Care. She was a committee member for the Institute of Medicine's Leading Health Indicators for Healthy People 2020 and Living Well with Chronic Illness: A Call for Public Health Action. Early in her career she served as a Peace Corps volunteer working for Thailand's Ministry of Public Health and served for six years in the US Army Reserves. Dr. Nielsen holds an MPH from the George Washington University and a PhD from the Johns Hopkins School of Public Health, in the Department of Health Policy and Management.



**HOPE R. WITTENBERG, MA**  
**Director, Government Relations, Council of Academic Family Medicine**

Ms. Wittenberg came to Washington in 1981, after getting a Master's degree in physical anthropology from the University of Massachusetts, Amherst. She began work on Capitol Hill for the Hon. Hamilton Fish, Jr. (R-NY), serving as his legislative assistant, staffing many issues including Medicare, Medicaid and other health programs.

For the past 28 years she has worked in a government relations capacity for various physician organizations representing them on issues ranging from Medicare, physician payment, CLIA, the ESRD program and appropriations.

Almost twenty-two years ago, she opened the Washington office of Organizations of Academic Family Medicine as Director, Government Relations. This office, now known as the Council of Academic Family Medicine, represents STFM, ADFM, AFMRD, and NAPCRG on Capitol Hill and with the Department of Health and Human Services on issues of interest to academic family medicine such as funding for primary care research, health professions training (Title VII), and workforce (including Medicare GME.)



**NANCY MASON MACLELLAN**  
**Manager, Major Initiatives, Canadian Institute of Health Research**

Nancy Mason MacLellan is the Manager of Major Initiatives in the Research, Knowledge Translation and Ethics Portfolio at the Canadian Institutes of Health Research. Having been with CIHR for over 14 years, she has managed funding initiatives for researchers across the spectrum of health research and at all career stages. Nancy's current responsibilities include the management and oversight of the Strategy for Patient-Oriented Research (SPOR) as well as the implementation of CIHR's Patient and Citizen Engagement Strategies.



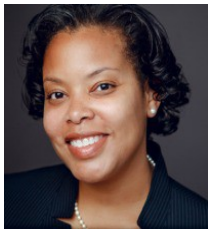
**DAVID HICKAM, MD, MPH**  
**Program Director Patient-Centered Outcomes Research Institute**

David Hickam, MD, MPH, is the Program Director of the Clinical Effectiveness Research program at the Patient-Centered Outcomes Research Institute (PCORI). He is responsible for developing PCORI's research program that evaluates comparisons among alternative clinical strategies in a broad range of clinical domains, and he also provides staff support to the PCORI Methodology Committee.

Hickam is a specialist in internal medicine and has 30 years of experience as a health services researcher. His past research has focused on strategies for improving health care outcomes among adults with chronic diseases. Hickam previously held the rank of professor in the Department of Medicine at Oregon Health and Science University (OHSU). He also held a joint faculty appointment in OHSU's Department of Medical Informatics and Epidemiology. He was a senior investigator in the Oregon Evidence-based Practice Center at OHSU and also served as co-director of the health services research and development program at the Portland VA Medical Center. He has expertise in a broad range of both quantitative and qualitative research methodologies.

In 2005, he became the founding director of the John M. Eisenberg Clinical Decisions and Communications Science Center, funded by the Agency for Healthcare Research and Quality. The Eisenberg Center has developed innovative approaches for helping people use evidence-based information to participate in decision making about their health care.

Hickam received his BA from Stanford University, an MD from the University of California, San Francisco, and a MPH from the University of California, Berkeley.



**COURTNEY CLYATT, MA**  
**Senior Program Associate, Patient-Centered Outcomes Research Institute**

Courtney Clyatt, MA, is a Senior Project Associate for Engagement at the Patient-Centered Outcomes Research Institute (PCORI). She comes to PCORI with more than 10 years of experience in public health and project management. In her position, she will play a vital role in the Engagement Awards program and, specifically, the Pipeline to Proposal Awards, which will fund community-building and engagement projects.

Clyatt has worked extensively with community-based health organizations in the District of Columbia and has provided them with program oversight and technical assistance. She recently led the implementation of the 2005-2010 DC Cancer Control Plan and has also led the development of the 2013-2018 DC Cancer Control Plan while working with the DC Cancer Consortium.

Clyatt is a graduate of The George Washington University, where she completed her studies in international politics at The Elliott School for International Affairs and Global Health Program Design Monitoring and Evaluation at the School of Public Health and Health Sciences. Her master's thesis research explores the correlation between insurance status and health outcomes following a colorectal cancer diagnosis.





**TSAHAI TAFARI, PhD**  
**Associate Director, Patient-Centered Outcomes Research Institute**

Tsahai Tafari, PhD, is the Associate Director, Science at the Patient-Centered Outcomes Research Institute (PCORI). She oversees the work of the Merit Review Officers and promotes coordination among PCORI's teams to ensure the scientific integrity of the merit review program.

Tafari joins PCORI from SRA International, where she was a scientific review manager. While at SRA, she managed the scientific peer review process for several large research programs on behalf of the Congressionally Directed Medical Research Programs of the Department of Defense. She also contributed to several process-improvement initiatives and program-evaluation projects. She began her tenure at SRA as a scientific review officer.

Before joining SRA, Tafari worked as a medical writer for MedThink Communications, where she created deliverables on therapeutic areas including pulmonary arterial hypertension, ulcerative colitis, and coagulative disorders. Her experience includes basic scientific research, clinical data analysis, peer review and program management, and program evaluation.

Tafari has a BA in history from Columbia University, and a PhD in biomedical sciences from the University of California at San Diego, with a focus on cell biology. She completed post-doctoral training at Duke University and at the National Institute of Environmental Health Sciences.





## **Key Messages for Advocating the Importance of Primary Care and Primary Care Research**

- The overall health of a population is directly linked to the strength of its primary health care system. A strong primary care system delivers higher quality of care and better health for less cost.
- Primary care provides a “medical home” and considers the whole person, as they exist in family, community, and population, including multiple illnesses, preventive care, health promotion, and the integration of mind and body.
- Primary care is:
  - Complex and comprehensive
  - Where most people first bring their symptoms and health concerns and have their first touch with the health care system
  - Where people develop healing, trusting relationships with their physician and other primary care providers
- Primary care research includes:
  - Translating science into the practice of medicine and caring for patients
  - Understanding how to better organize health care to meet patient and population needs
  - Evaluating innovations to provide the best health care to patients
  - Engaging patients, communities, and practices to improve health
- The majority of health care takes place in primary care practices.
- And yet, the majority of research funding supports research of one specific disease, organ system, cellular or chemical process – not for primary care.
- Very little is known about important topics such as how primary care services are best organized, how to maximize and prioritize care, how to introduce and disseminate new discoveries so they work in real life, and how patients can best decide how and when to seek care.
- We call for additional funds to be allocated to primary care research to be used for *<insert request here>*.

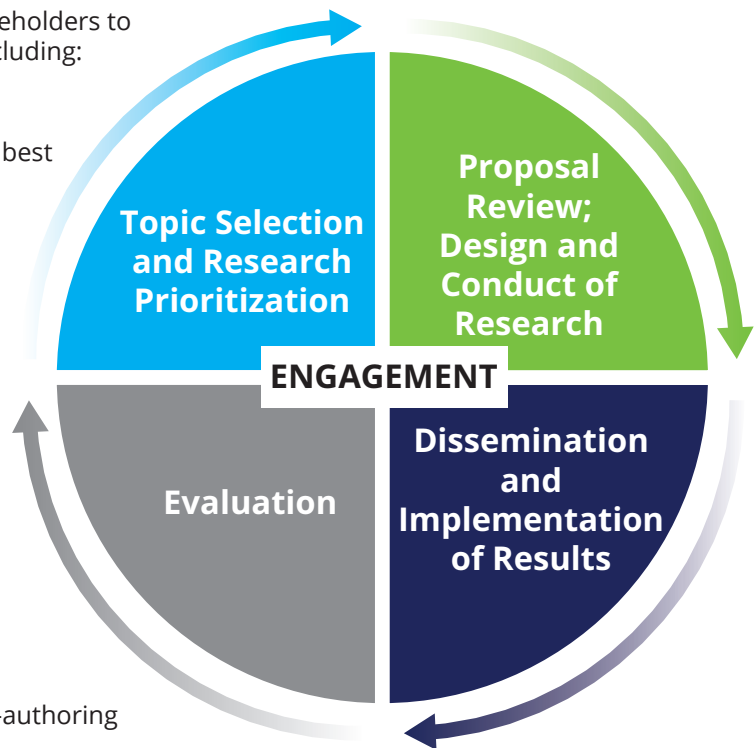
## PCORI ENGAGEMENT: RESEARCH DONE DIFFERENTLY

PCORI funds research that compares the effectiveness of preventive, diagnostic, and treatment options to determine what works best for patients given their preferences and circumstances.

In doing so, we seek to change the way health research is done so that it actively involves the “end-users” of study results – patients and family caregivers, clinicians, hospitals and health systems, purchasers, payers, industry, policymakers and training institutions – throughout the research process. We believe this means the results are more likely to be relevant, useful, trusted, and taken up in practice.

PCORI provides many ways for patients and other stakeholders to become actively engaged in research and our work, including:

- **Suggesting which research questions to ask**  
e.g., “I want to know which strategies are best to manage asthma.”
- **Helping prioritize what we fund**  
e.g., participating in working groups, PCORI Advisory Panels, or reviews on researchers’ applications for PCORI funding.
- **Participating in a study**  
e.g., partnering as a co-investigator, consultant, or member of a community or stakeholder group contributing to a study.
- **Sharing results**  
e.g., sharing research findings through membership groups, starting an online conversation, presenting at events, or co-authoring papers about a study’s findings.



## ADVISORY PANEL ON PATIENT ENGAGEMENT

The Patient Engagement Advisory Panel (PEAP) is a multi-stakeholder panel of patients, researchers, and other stakeholders tasked with helping PCORI realize our engagement goals. The panel convenes several times a year to discuss various patient and other stakeholder issues and has already provided invaluable advice and input on several major initiatives, including the creation of the Engagement Rubric, the development of the Engagement Officer concept, and the formation of the Ambassadors program. The PEAP also served as our inaugural Ambassadors and many are involved in other PCORI initiatives.

## RESOURCES TO SUPPORT ENGAGEMENT IN RESEARCH

Our **PCORI Engagement Rubric** provides researchers and those interested in becoming partners on research teams with guidance on how to best involve these key individuals in engagement plans and throughout the research process. The rubric illustrates various options for engagement, drawing on examples from studies PCORI has selected for funding.

Our **Engagement Officers** work closely with Program Officers to oversee the engagement in our funded projects and to collect and share examples of strong patient and stakeholder engagement.

**Pipeline to Proposal Awards** offer seed funding to build a national community of patients, other stakeholders, and

researchers able to participate in research and create partnerships that lead to high-quality research proposals. There are different tiers of funding available (see below) depending on how developed the proposals are:



**Tier I:** Building of community and capacity necessary to later develop a research project

**Tier II:** Maturation of research partnerships with the goal of receiving PCORI or other funding

**Tier III:** Proposal development, targeting advanced potential research partnerships

## EUGENE WASHINGTON PCORI ENGAGEMENT AWARDS

Named in honor of PCORI's first Board of Governors Chair, this program offers funding awards to patients, caregivers, clinicians, and other healthcare stakeholders to support work related to patient-centered outcomes research or to introduce them to PCORI's research funding process.

The program offers three categories of awards:

- **Knowledge Awards**
- **Training and Development Awards**
- **Dissemination Awards**

## PCORI AMBASSADORS SPREAD THE WORD

**PCORI Ambassadors** are patients, organizations, and other healthcare stakeholders who, as volunteers, share PCORI's vision and mission with their communities, participate as partners in research, and help ensure the spread and use of information generated by PCORI-funded projects.

## EVENTS FOR SHARING AND LEARNING

We convene representatives from across the healthcare community for information exchange, discussion, and partnership building in webinars, regional workshops, engagement roundtables, and targeted workgroups.

## Get Involved with PCORI Opportunities:

<http://www.pcori.org/content/get-involved>

### Suggest a Patient-Centered Research Question

We invite patients, caregivers, clinicians, and other healthcare community members to submit the specific questions they would like us to consider for funding. The suggestions received will be evaluated through our process to identify and prioritize specific topics to study. *Submit a question about a healthcare issue of particular importance to you.*

### Provide Input

We periodically provide formal public comment periods to obtain and incorporate public input and feedback on our work, including draft reports, policies, and initiatives. *Explore upcoming opportunities to provide input on our work.*

### Review Funding Applications

We invite professional and lay audiences to be reviewers of research applications submitted in response to our Funding Announcements. *Hear why patients and other stakeholders are helping evaluate our funding applications and how you can apply to become a reviewer.*

### Join an Advisory Panel

We develop and utilize multi-stakeholder Advisory Panels of representatives from across the healthcare community to help advance our scientific and engagement work. *Learn how you can apply to join a panel.*

### Participate in PCORI Events

We convene representatives from across the healthcare community for information exchange, discussion, and partnership building in webinars, regional workshops, engagement roundtables, and targeted workgroups. *We welcome public participation in these events in different capacities; learn more about how you can participate.*

### Become a PCORI Ambassador

Our Ambassador Program aims to help patients, organizations, and other stakeholders share our vision and mission with their communities, participate as full partners in research, and help ensure the sharing and use of information generated from PCORI-funded projects. *Learn about the Ambassador Program and how you can apply.*









