
ENGAGING PATIENTS & OTHER STAKEHOLDERS IN TRANSLATIONAL RESEARCH: TOOLS AND BEST PRACTICES FOR RESEARCH TEAMS



Community-Academic Partnerships

UW Institute for Clinical and Translational Research

PLANNING COMMITTEE CHAIR



Maureen Smith, MD, PhD, MPH, Planning Committee Chair. In her capacity as Director of the Community-Academic Partnership program for the UW-Madison Institute for Clinical & Translational Research, Dr. Smith provides the leadership and resources necessary to prepare investigators to meet the NIH challenge to “make engagement the norm” in translational research. In addition to acting as Principal Investigator for a funded PCORI award and numerous other grants, Dr. Smith mentors junior investigators and teaches courses such as *Introduction to Translational Outcomes Research* and *Quality of Healthcare*. Dr. Smith has a long-standing interest in

improving the quality of care in our healthcare delivery system. Her research evaluates the impact of health system changes on access to and quality of medical care for aging and chronically ill persons. She has extensive experience in the use of health care data for measurement of the quality of care and improvement of health. Dr. Smith is also Director of Health Innovation Program, Professor in the Department of Population Health Sciences, and Family Medicine and Community Health, and Associate Director for Population Sciences at the UW Comprehensive Cancer Center.

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DAY ONE PRESENTERS



Betty Chewing, PhD is a Professor in the School of Pharmacy whose research has integrated the perspectives of patients, providers, teachers, administrators and other community partners throughout her research career. In collaboration with Elizabeth Cox, her goal is to assist people in planning meaningful, iterative stakeholder engagement through workshops and templates, which assist blended stakeholder groups. It is her belief that diversity of voices and views are needed to improve the research process and achieve the most meaningful research outcomes for the target group.

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Nichelle Cobb, PhD, is the Director of the Health Sciences Institutional Review Boards (IRBs) at the University of Wisconsin-Madison and has worked with IRBs since 1999. She has been involved in the formation of several statewide and regional IRB consortia to streamline IRB oversight of multi-site research. In addition to her duties as an IRB Director, Nichelle acts as the Chief Regulatory Operations Officer for Implementation for SMART IRB. SMART IRB is a project sponsored by the National Center for Advancing Translational Science (NCATS), an agency within the National Institutes of Health, which created a standardized national IRB agreement that

supports IRB reliance arrangements between institutions. Nichelle also works on several projects with Patient Centered Outcomes Research Network (PCORNet), such as serving as member of a working group to establish a common IRB model and advising the Genetic Alliance IRB regarding implementation of the SMART IRB agreement in support of a study using a single IRB for several Patient Powered Research Network (PPRN) sites. Aside from her work on single IRB review, Nichelle acts as a site visitor for the Association for the Accreditation of Human Research Protection Programs (AAHRPP).

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Elizabeth Cox, MD, PhD is Director of the Program of Research on Outcomes for Kids (PROKids) at the University of Wisconsin-Madison School of Medicine and Public Health and a practicing pediatrician. Dr. Cox has been the principal investigator (PI) of multiple research awards that leverage the voices of children and their families to deliver safer, higher quality pediatric care. Currently, she is PI of a PCORI-funded multi-site trial examining the effectiveness of family-centered interventions for children with type 1 diabetes and co-PI on an NIH U19 to evaluate clinical utility of PROMIS pediatric item banks for chronically ill children and their families. She also serves as co-

investigator or consultant on multiple other PCOR initiatives and funded grants and has been a member of PCORI's Improving Healthcare System's Advisory Panel. Through her experiences and training, Dr. Cox has developed extensive knowledge and skills to integrate the diverse perspectives of patients, caregivers, and other stakeholders across the research trajectory. She is also an Associate Professor of Pediatrics and Population Health Sciences at University of Wisconsin-Madison School of Medicine and Public Health.

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Betty Kaiser, PhD, RN is Director of Stakeholder Training with the Wisconsin Network for Research Support (WINRS) based at the UW-Madison School of Nursing. She works with WINRS colleagues Gay Thomas and Kaitlin Svabek to provide in-depth consultation on stakeholder engagement to research teams. Her focus is developing tailored training programs that prepare stakeholders for their work on specific project, as well as train-the-trainer programs that help research teams build skills for delivering stakeholder training programs. About WINRS: <http://winrs.son.wisc.edu/>

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Gay Thomas, MA is Director of Stakeholder Engagement with the Wisconsin Network for Research Support (WINRS) based at the UW-Madison School of Nursing. She works with WINRS colleagues Betty Kaiser and Kaitlin Svabek to advise research teams on effective processes and materials to engage patients and community members as study participants or project stakeholders. Gay helps researchers develop strategic meeting agendas and activities for stakeholder groups to produce useful outcomes for the research team. About WINRS: <http://winrs.son.wisc.edu/>

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STAKEHOLDER ENGAGEMENT EXPERTS FACILITATING DAY 1 SMALL GROUP CONSULTATIONS

Elizabeth Cox, MD, PhD

Director of the Program of Research on Outcomes for Kids (PROKids), member of PCORI's Improving Healthcare System's Advisory Panel, and Associate Professor of Pediatrics and Population Health Sciences at University of Wisconsin-Madison School of Medicine and Public Health

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Betty Chewning, PhD

Professor, School of Pharmacy and William S. Apple Distinguished Chair in Social/Administrative Sciences. Fellow in the APhA APRS and has served on several NIH and CDC study section review committees. Facilitates an ICTR-CAP partner program offering Stakeholder Engagement Resources to UW ICTR members.

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Gwen Costa Jacobson, PhD

Postdoctoral Trainee in the Family Medicine, Pediatrics. Gwen works closely with Dr. Elizabeth Cox (Pediatrics) on research relating to the delivery of family-centered care in both inpatient and outpatient settings, and with Dr. Betty Chewning (School of Pharmacy) on developing programs to facilitate the engagement of multiple stakeholders in patient-centered outcomes research.

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Sujani Kakumanu, MD

Clinical Assistant Professor, Division of Allergy, Pulmonary and Critical Care Medicine. Research interests include pediatric asthma care coordination with schools, the immune responses of adults residing in inner-city regions to innate and adaptive results stimuli, and the incidence of aspirin and penicillin allergy in the VA patient population.

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Jane Mahoney, MD

Professor, School of Medicine and Public Health, Department of Geriatrics
Director of ICTR-CAP Dissemination & Implementation Core, Director of Community-Academic Aging Resource Network (CAARN), Director of the Wisconsin Alzheimer's Institute (WAI). She is also an Affiliate Faculty of the UW Institute on Aging.

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Edmond Ramly, PhD, MS

Postdoctoral health systems engineer in the UW College of Engineering, Center for Health Systems Research and Analysis. Co-Investigator and engagement liaison with Dr. Christine Bartels on current funded ICTR Patient-Centered Outcomes Research award and collaborator on multiple research projects involving stakeholder engagement methods.

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Nasia Safdar, MD, PhD

Associate Chief of Staff for the Office of Research and Development at the Williams S. Middleton Veterans Hospital and Associate Professor, UW School of Medicine & Public Health.

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DAY TWO PRESENTERS



Melody Bockenfeld, MPH, BSN is the Dissemination & Implementation (D&I) Program Manager at the University of Wisconsin Institute for Clinical and Translational Research (ICTR). The ICTR D&I program focuses on accelerating the pace of disseminating research findings and increasing the implementation and use of effective interventions in practice. Melody received her Master of Public Health and Bachelor of Nursing degrees from the University of Illinois, at Chicago. She has worked in health care and public health in Chicago and Wisconsin for over 30 years; including hospital and community-based Maternal Child Health programs, regional perinatal systems, and 12 years as a Local Public Health Officer in Outagamie County, Wisconsin. Melody has served on numerous community boards and committees, and has also served in leadership positions for the Wisconsin Public Health Association and Wisconsin Association of Local Health Departments and Boards.

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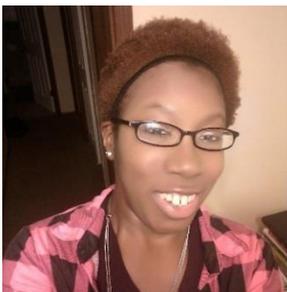
Sarah Davis, J.D., MPA is Clinical Associate Professor of Law and Associate Director of the Center for Patient Partnerships. She partners with researchers and healthcare teams to advance health. A current pilot project with Dr. Pandhi aims to identify key clinic factors and cost-effective educational approaches to support value-added patient engagement in quality improvement. Her approach to patient engagement is informed by her work in patient advocacy at the Center's clinic, where students from multiple disciplines offer free legal, medical, and social-support advocacy to patients navigating the health care system.

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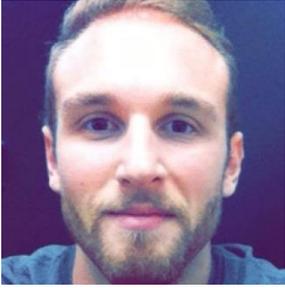


Reed Gaines, holds a B.A. in English from Vassar College and an M.F.A. in Literary Arts from Brown University. Before joining DIPEX as a Dissemination and Implementation specialist, he worked for Google's AdWords teams as an Account Strategist. Reed lives and works in Grand Rapids, Michigan.

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Myra Hillen, Patient Ambassador, is a Milwaukee native who has been involved in the arts since childhood. For most of her adult life she has been learning how to deal with her depression and anxiety. She has been inspired by speaking about her experience and has decided to make reducing the stigma around mental illness her career. When not working, Myra spends plenty of time with her husband and friends. She also sings and plays in a band called Astral/Subastal.



Colin Kluender, Patient Ambassador, had depression in middle school. He has attempted suicide and has OCD. Non-residential day therapy, medications, and practicing gratitude have helped put Colin on the healing path. He works and attends college.



Nancy Pandhi, MD, MPH, PhD is an Assistant Professor in the UW-Madison Department of Family Medicine and Community Health and a family medicine doctor at Access Community Health Centers. Her research program is directed towards effective ambulatory care redesign for vulnerable populations, with a focus on understanding the patient perspective.

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Caitlin Scott, MLIS, is the Health Equity Outreach Specialist for the Collaborative Center for Health Equity (CCHE), and provides a wide range of support for the Health Equity Leadership Institute (HELI). Caitlin handles social media and communications for CCHE, HELI and assists with the ICTR website. Caitlin is also the Pilot Grant Administrator for the ICTR Advancing Health Equity and Diversity (AHEAD) Program, and acts as the initial point of contact for all visitors to the Center's Health Sciences Learning Center suite.

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