

# ENGAGING KEY PARTNERS TO DESIGN AND CONDUCT HIGH QUALITY CLINICAL RESEARCH

## Course Co-Directors



**Elizabeth Cox, MD, PhD** is the Director of the Program of Research on Outcomes for Kids (PROKids) at the University of Wisconsin-Madison School of Medicine and Public Health (UWSMPH) 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 the 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 clinical research projects that are guided by stakeholders and has been a member of PCORI's Improving Healthcare System's Advisory Panel. She is an Associate Professor of Pediatrics and Population Health Sciences at UWSMPH.

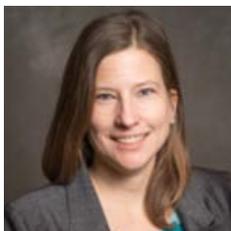
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**Nasia Safdar, MD, PhD** is the Associate Chief of Staff for the Office of Research and Development at the William S. Middleton Veterans Hospital. Dr. Safdar's research focuses on healthcare-associated infections. She is the PI of the QUERI-partnered evaluation project and a PCORI grant to develop a panel of engaged veterans with lived experience with an infection and build a shared research agenda in this area.

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## Presenters & Faculty Planning Committee



**Nicole Brys, MPH** is the Dissemination and Implementation Researcher on Dr. Safdar's research team at the William S. Middleton Veterans Hospital Research Program. Her work focuses on how input from patients, providers, and other stakeholders can be effectively elicited and understood to make knowledge from research more relevant and useful.

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**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 Dr. 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 and a range of resources to support single IRB review. As part of the SMART IRB project she also co-leads a working group to harmonize approaches to reportable events. In addition, she is a member of several working group to establish support for single IRB model review of multi-site research (e.g., for the Patient Centered Outcomes Research Network and the Clinical Trials Transformation Initiative). Nichelle also is a site visitor for Association for the Accreditation of Human Research Protection Programs (AAHRPP). Nichelle served as a member of the Public Responsibility in Medicine & Research Workshop/Didactic Subcommittee.

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**Sarah Davis, JD, MPA** is a Clinical Associate Professor of Law and Associate Director of the Center for Patient Partnerships (CPP). Her approach to stakeholder engagement is informed by advocacy experience at CPP's clinic, where students from multiple disciplines offer free legal, medical, and social-support advocacy to patients navigating the health care system. She is wrapping up a project with Dr. Pandhi which identified key clinic factors and desired outcomes to support value-added patient engagement in quality improvement.

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**Sarah Esmond, MS** is the Administrative Director of the [UW Institute for Clinical and Translational Research](#) and the [UW Collaborative Center for Health Equity](#) (CCHE). She provides project management leadership to multiple initiatives across the portfolio of programming in clinical and translation research, community-engaged research, and health equity scholarship. She works closely on the implementation of the *All of Wisconsin @ UW* precision medicine research program sponsored by NIH. She also works collaboratively with faculty and staff affiliates of CCHE and the UW Health Patient and Family Advisor Partnership Program to strengthen patient-centered and stakeholder-engaged research partnerships occurring at UW.

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**Betty Kaiser, PhD, RN** is the Director of Stakeholder Training with the Wisconsin Network for Research Support (WINRS) based at the UW-Madison School of Nursing. She provides in-depth consultation on stakeholder engagement to research teams, with a focus on developing tailored orientation programs for project-specific patient advisory boards, as well as train-the-trainer programs that help research teams build skills for delivering stakeholder orientation programs. About WINRS:

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**Nancy Pandhi, MD, MPH, PhD** is an Assistant Professor in the UW-Madison Department of Family Medicine and Community Health and practices at the William T. Evjue clinic of Access Community Health Centers. She founded and co-directs the Primary Care Academics Transforming Healthcare (PATH) collaborative. She currently chairs in the qualitative research committee of the Health Experiences Research Network. Her research program is directed towards effective ambulatory care redesign for vulnerable populations, with a focus on increasing understanding of patients' perspectives.

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**Ann Sexton, MPH, CCRA** Ann has been a Clinical Research Coordinator with the Asthma, Allergy, and Pulmonary Clinical Research Unit since 1995. As lead coordinator for the UW-Madison site's NIH NHLBI's Asthma Clinical Research Network (ACRN-1993-2008) and AsthmaNet (2008-2018) and the Recruitment Coordinator for Pediatric studies (2017-2018). She was responsible for ensuring the successful recruitment goals for each of the studies. In order to reach recruitment goals, she has utilized a variety of recruitment methods. She has

experience with research registries, mass emails, social media, electronic medical record searches, TV, print, and digital advertising. She has worked with community liaisons to help promote minority diversity in studies. Ann has recently expanded her role as the ICTR Recruitment Specialist. In this role, Ann has facilitated the development of a Recruitment Steering Committee (RSC). The RSC is made up of representatives from a variety of study teams. Ann and the RSC will bring recruitment expertise to strengthen recruitment infrastructure by developing innovative strategies to improve enrollment in clinical research system-wide.

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**Maureen Smith, MD, PhD, MPH** is Director of the UW Institute for Clinical & Translational Research Community Academic Partnerships (ICTR-CAP) core and the Director of the UW Health Innovation Program. In these roles, she is responsible for coordinating the development of new resources for community-partnered research across UW schools, colleges, departments, and centers. 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. Her recent grants (R01 HS018368; R01 CA144835; R21 HS021899; PCORI HSRP20164071) involve close collaboration with health care systems across the state and nation. Her current PCORI grant is a multi-site collaborative study with Massachusetts General Hospital, Harvard University, and the University of Iowa to study case management programs in healthcare systems across the country. With funding from the Wisconsin Partnership Program, Dr. Smith is also collaborating with the Wisconsin Collaborative Center for Health Equity to measure and publicly report disparities in the quality of care for health systems across the state of Wisconsin. Email: [maureensmith@wisc.edu](mailto:maureensmith@wisc.edu)



**Gay Thomas, MA** is the Director of Stakeholder Engagement with the Wisconsin Network for Research Support (WINRS) based at the UW-Madison School of Nursing. Her background encompasses a broad range of professional positions on Capitol Hill, with Planned Parenthood, for several health insurance organizations, and on multiple health sciences research projects. Her work with WINRS focuses on creating tailored stakeholder engagement strategies that empower patients and community members to draw on their own lived experience to give “expert advice” to researchers on how best to connect/communicate with people researchers seek to reach. She is passionate about helping research teams build and sustain effective stakeholder partnerships which benefit all participants and produce meaningful research outcomes. About WINRS: <http://winrs.son.wisc.edu/>. Email: [grthomas@wisc.edu](mailto:grthomas@wisc.edu)



**Thuy Dan Tran, BS** is a Research Specialist for the Department of Pediatrics. She is part of the Program of Research on Outcomes for Kids (PROKids) team under the leadership of Dr. Elizabeth Cox. Her role has utilized stakeholder input to increase recruitment and retention of study participants, to disseminate study findings in online toolkits, and to create online survey measures. She also has experience coordinating workshops and short courses that focus on teaching others the value of stakeholder engagement in their research. Email: [tran4@wisc.edu](mailto:tran4@wisc.edu)



**Torrey Tiedeman**, is a core programming event director with the University of Wisconsin-Madison VETS (Veterans, Educators, and Traditional Students). He served a four year enlistment in the United States Marine Corps as an active duty infantryman, deploying once to Helmand Province, Afghanistan and once to Okinawa, Japan. He is currently a fourth-year undergraduate student studying economics and political science. Email: [ttiedeman@wisc.edu](mailto:ttiedeman@wisc.edu)