

WORKSHOP ON

Translating
CKD Research
into Improved
CLINICAL
Outcomes

NATCHER CONFERENCE CENTER
NATIONAL INSTITUTES OF HEALTH
OCTOBER 18-19, 2010



Agenda: Day 1

Monday, October 18, 2010

- 8:00 a.m. **Registration**
- 9:00 a.m. **Opening Remarks - Welcome and Objectives of the Workshop**
Robert Star, National Institute of Diabetes and Digestive and Kidney Diseases (NIDDK)
- 9:10 a.m. **Background - Chronic Kidney Disease (CKD) and Phase 2 Translational (T2) CKD Research into Improved Clinical Outcomes**
Andrew Narva, NIDDK
- 9:30 a.m. **Keynote Speaker - Science of T2 Translation**
Russell Glasgow, National Cancer Institute

10:10 a.m. **Break**

Collaborating in T2 Translation in CKD

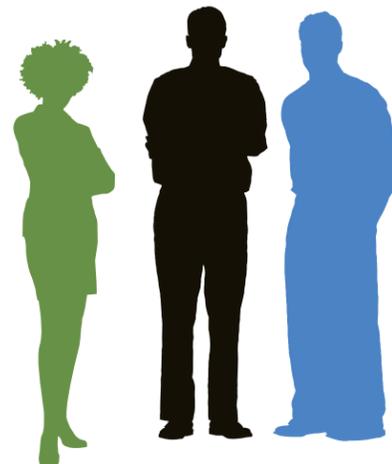
Moderator: Eduardo Ortiz, National Heart, Lung, and Blood Institute

- 10:30 a.m. **Collaboration with Department of Veterans Affairs' (VA) Quality Enhancement Research Initiative**
David Atkins, VA
- 10:50 a.m. **Collaboration with Community Health Centers**
David Stevens, National Association of Community Health Centers
- 11:10 a.m. **Collaboration with the Centers for Disease Control and Prevention (CDC)**
Desmond Williams, CDC
- 11:30 a.m. **Panel Discussion**
- 12:00 p.m. **Lunch**

Challenges in T2 Translation Research

Moderator: Ann Bullock, Indian Health Service

- 1:00 p.m. **Multidisciplinary Team-based Chronic Care**
Barry Carter, University of Iowa
- 1:30 p.m. **Reducing Medication Discrepancies During Transitional Care**
Cindy Corbett, Washington State University
- 2:00 p.m. **Health Literacy**
Kerri Cavanaugh, Vanderbilt University Hospital
- 2:30 p.m. **Panel Discussion**
- 2:50 p.m. **Charge to Breakout Groups**
Andrew Narva, NIDDK
- 3:00 p.m. **Break**
- 3:15 p.m. **Breakout Sessions**
- 5:00 p.m. **Adjourn**



Agenda: Day 2

Tuesday, October 19, 2010

- 8:00 a.m. **Registration**
- 8:30 a.m. **Plenary Speaker - T2 Translation as a Means to Reduce Disparities**
Ebony Boulware, Johns Hopkins School of Medicine and Johns Hopkins Bloomberg School of Public Health
- 9:10 a.m. **Presentations by the Breakout Groups with Discussion**
Moderator: Katherine Tuttle, University of Washington School of Medicine
- 10:30 a.m. **Break**
- 10:45 a.m. **Response: What the National Health Service (NHS) Has Done**
Donal O'Donoghue, NHS
- 11:30 p.m. **Summary**
Andrew Narva, NIDDK
- 12:00 p.m. **Adjourn**



Breakout Session Questions

Room E1/E2: **Designing interventions to reach high-risk populations**

William McClellan

- How can high-risk populations (besides race/ethnic groups) in the U.S. and territories be identified?
- How should medical care teams approach each of these populations?
- What communication tools could be utilized to increase awareness and knowledge of chronic disease and the need for ongoing care?
- Who on the care team should bear the most responsibility for the intervention?
- Are physicians a part of the problem in carrying out such interventions?
- How should we measure the success/failure of these interventions?

Room A: **Nephrology/primary provider collaboration**

Katherine Tuttle/Ann Bullock

- Years ago, subspecialists would “steal” patients from primary care providers. How should nephrologists approach primary care practitioners (MD, NP, etc.) to decrease this potential barrier?
- Should communities move toward a “medical home” concept in caring for patients with chronic disease?
- Should the Centers for Medicare & Medicaid Services, Health Resources and Services Administration, or a State government entity set up guidelines for referral?

Room G1/G2: **Where does CKD fit in chronic disease management?**

Thomas Sequist

- Should CKD always be considered in the management of diabetes, hypertension, and congestive heart failure?
- How does CKD affect chronic disease management with respect to medications? Are primary care providers competent to do this?
- CKD is typically a silent disease. How can we make it more visible to the patient?
- Should programs such as “know your numbers” be implemented?

Room C2: **Designing multidisciplinary team interventions**

Barry Carter

- Who should be included on a multidisciplinary team?
- Who should lead the team?
- How should reluctant physicians be approached to participate?
- Will electronic health records assist with team management?
- How does government (Federal/State) promote multidisciplinary teams?
- How can we measure a team’s efficacy or performance?

Room C1: **Literacy/numeracy**

Kerri Cavanaugh

- How should we approach a community made up of multiple ages, cultures, and languages?
- What approaches might be used to communicate with different cultures:
 - Settings: barbershops, hair salons, pool halls, faith-based settings, etc.
 - Format: print, media, face-to-face, individual vs. group, social networks
 - Participants: local leaders/champions, facilitating buy-in, building trust
- What should the patient know about his/her disease?
- How will literacy/knowledge be tested in order to develop and then evaluate any maneuver?
 - What approaches will be used in individual literacy assessment to minimize shame and other psychological distress often associated with limited literacy?
 - If a goal of the intervention program is to communicate information, how will the effectiveness of that exchange be evaluated? Existing validated measure? Development of a new instrument?
- What strategies can be used to address limited health literacy in vulnerable populations?
 - For print materials
 - For verbal communication exchanges
- How can the design of the intervention or program be sustainable, especially in vulnerable populations?

Room D: **Performance measures and tracking**

Puneet Sahni/Sharon Wyatt

- What is a good performance measure?
- What are some of the barriers in tracking performance measures?
- Can electronic health records and chronic disease registries help?
- What are some of the performance measures that providers have found useful?



Presenter and Moderator Bios

David Atkins, MD, MPH, is the director of the Quality Enhancement Research Initiative (QUERI) program in the Office of Research and Development of the Veterans Health Administration (VHA). In that role, he oversees a network of 10 research centers dedicated to studying and improving the implementation of new practices to improve the quality of care in the VA health system. Before coming to the VHA, Dr. Atkins spent 12 years at the Agency for Healthcare Research and Quality, providing scientific oversight to their work on evidence-based practice, care management, and comparative effectiveness. He is a board-certified internist and clinical epidemiologist. He received his MD from Yale University, completed his residency at University of Pittsburgh Medical Center, and received his MPH from the University of Washington, where he also completed a Primary Medicine Fellowship. He has published widely on issues of clinical prevention, comparative effectiveness, translating evidence into practice, and implementation research.

Ebony Boulware, MD, MPH, is an associate professor of medicine and epidemiology in the Departments of Medicine and Epidemiology, as well as the Welch Center for Prevention, Epidemiology, and Clinical Research at the Johns Hopkins Medical Institutions in Baltimore, Maryland. Her major research interests include identifying ways to improve patients' and physicians' treatment decision-making for CKD care, eliminating ethnic/race disparities in CKD care, and identifying patient, physician, and system-level barriers to the delivery of appropriate care to patients with CKD. Her most recent work identified patient and physician barriers to the delivery of guideline concordant care for patients with CKD, as well as patient, physician, and population factors affecting the receipt of optimal therapies for kidney disease, such as kidney transplants. Her ongoing research includes studies to develop and test educational and behavioral interventions to improve patient decision-making about treatment options for CKD and studies of physicians' management and coordination of care for patients with CKD. She also performs research on the comparative effectiveness of treatment strategies for patients with end-stage renal disease.

Ann Bullock, MD, is a board-certified family physician who has worked for the Indian Health Service (IHS) in Cherokee, North Carolina since 1990. Since 2007, she has been the IHS national chief clinical consultant for family medicine and the course director for IHS' annual primary care conference, *Advances in Indian Health*. Beginning in 2000, she served as an advisor to the IHS Division of Diabetes Treatment and Prevention and, in 2009, became its clinical consultant. In these roles, she has been an author on numerous diabetes treatment guidelines, best practices, and standards of care. Dr. Bullock serves on the Federal Kidney Interagency Coordinating Committee and on the National Kidney Disease Education Program's Coordinating Panel. She is an enrolled member of the Minnesota Chippewa Tribe and a member of the Association of American Indian Physicians.

Barry Carter, PharmD, received his BS in pharmacy from the University of Iowa (1978), PharmD from the Medical College of Virginia (1980), and completed a postdoctoral fellowship in family practice at the University of Iowa (1981). He is currently a professor in the Division of Clinical and Administrative Pharmacy, College of Pharmacy and a professor and associate head for research in the Department of Family Medicine, the Carver College of Medicine, at the University of Iowa. Dr. Carter is an internationally recognized expert in hypertension, organizational change to improve blood pressure control, guideline adherence, and multidisciplinary approaches to improving blood pressure control. He is the director of the National Interdisciplinary Practice-Based Research Network (PBRN)—the first interdisciplinary-based PBRN focused on clinical pharmacists within family medicine clinics recognized by the Agency for Healthcare Research and Quality. Dr. Carter is a fellow in the American Heart Association Council on High Blood Pressure Research and in the American College of Clinical Pharmacy. He was a member of the National Heart, Lung, and Blood Institute's National High Blood Pressure Education Program Committee, and a member of the Fifth, Sixth, and Seventh Joint National Committees (JNC) on Prevention, Detection, Evaluation, and Treatment of High Blood Pressure (JNC 5, 6, and 7), and was recently appointed to JNC 8.

Kerri Cavanaugh, MD, MHS, is an assistant professor of medicine in the Division of Nephrology and Center for Health Services Research at Vanderbilt University Medical Center. She graduated from Yale Medical School and completed her residency/fellowship in nephrology training at Johns Hopkins School of Medicine. She also completed a Masters in Health Science in Clinical Epidemiology at the Johns Hopkins Bloomberg School of Public Health. Her research interests have centered in understanding how patients with complex chronic diseases learn about their disease and translate that information into effective self-care. One particular area of interest has been health literacy and numeracy in the care of patients with all stages of CKD and diabetes mellitus. Dr. Cavanaugh has received grant support from the National Kidney Foundation and the National Institute of Diabetes and Digestive and Kidney Diseases to examine health literacy and numeracy in patients with end-stage renal disease receiving hemodialysis therapy, patients' knowledge of CKD, and barriers to effective communication related to kidney disease care.

Cynthia (Cindy) Corbett, PhD, RN, is an associate professor in the College of Nursing at Washington State University where she teaches and advises graduate students and coordinates the nursing PhD program. She also serves as a scholar in residence for the Providence Spokane Urban Hospitals and facilitates evidence-based practice and nursing research. Dr. Corbett's own research activities focus on strategies to improve chronic illness self-management. In conjunction with an inter-professional team, one of her lines of inquiry is a program of research to improve the safe use of medications following hospitalization. That line of research has been funded by the American Society of Health Systems' Pharmacists, the Robert Wood Johnson Foundation, and the Agency for Healthcare Research and Quality.

Russell Glasgow, PhD, is the deputy director for Dissemination and Implementation Science in the Division of Cancer Control and Population Sciences at the National Cancer Institute. He is a behavioral scientist who has conducted public health research in community, worksite, and health care settings, focused on the development and evaluation of practical, generalizable interventions. Dr. Glasgow has published over 350 peer-reviewed articles, received funding including a MERIT Award from the National Institute of Diabetes and Digestive and Kidney Diseases, as well as grant support from the National Cancer Institute; National Heart, Lung, and Blood Institute; National Institute of Child Health and Human Development; National Institute on Aging; and the Robert Wood Johnson Foundation. He also received the Society of Behavioral Medicine Award for Outstanding Scientist (2000). His former position was as co-director of the Center for Health Dissemination and Implementation Research at Kaiser Permanente Colorado. Dr. Glasgow's interests include: health communication, especially using multiple, new, and interactive technologies; and use of conceptual models for pragmatic research to help design, implement, evaluate, and report on studies to accelerate translation of research to practice and policy.

William McClellan, MD, MPH, is a professor of medicine and epidemiology at Emory University in Atlanta, Georgia. His recent work includes an evaluation of an ESRD Network intervention to improve influenza vaccination rates; investigation of geographic clustering of poverty and pre-hemodialysis care; studies of arteriovenous fistula use; and etiologic studies of CKD among participants in REGARDS, a population-based cohort study. He has published extensively on CKD epidemiology and health services and outcomes research.

Andrew Narva, MD, became the director of the National Kidney Disease Education Program at the National Institutes of Health in September 2006. From 1989 through 2006, he served as the chief clinical consultant for nephrology for the Indian Health Service (IHS), an agency of the Public Health Service, providing health care to over one million American Indians and Alaska Natives. He has served as a member of the Medical Review Board of ESRD Network 15 and as chair of the Minority Outreach Committee of the National Kidney Foundation (NKF). He serves on NKF's KDOQI Work Group on Diabetes in Chronic Diabetes and is a member of the Joint National Committee 8 Expert Panel. During 2002, Dr. Narva was recognized by the IHS National Council of Clinical Directors as Physician Leader of the Year and by the US Public Health Service as the Clinical Physician of the Year. In 2003, he received the U.S. Public Health Service Distinguished Service Medal, the highest recognition awarded to commissioned officers.

Donal O'Donoghue, BSc, MBChB, has been a consultant renal physician at Salford Royal National Health Service Foundation Trust since 1992. He was appointed the first national director for Kidney Care in England in 2007. After gaining degrees in physiology and medicine from Manchester University, Dr. O'Donoghue trained in renal and general internal medicine throughout the U.K. His research training was as a medical research council fellow at Hopital Necker in Paris. He was previously the inaugural president of the British Renal Society and a former treasurer and president-elect of the Renal Association. He chaired the National Service Framework for renal services and led the policy team and implementation strategy for kidney services in England. This included aligning kidney policy with public health and vascular risk reduction programs, early detection schemes, integrated care, and development of a chronic disease management model of care for kidney disease. Current research interests include epidemiology of CKD, the biology of progressive kidney disease, anemia management, and models of service delivery to optimize outcomes. He is also principle investigator for the kidney disease research intervention program in the Collaboration for Leadership in Applied Health Research and Care, and principle investigator on the Salford Chronic Renal Failure Standards Implementation Study. He has published more than 80 peer-reviewed papers, book chapters, and articles across the spectrums of nephrology, dialysis, and transplantation.

Eduardo Ortiz, MD, MPH, is a board-certified internist with an extensive background in evidence-based medicine, clinical informatics, and health services research. Dr. Ortiz is currently a senior medical officer in the Division for the Application of Research Discoveries at the National Heart, Lung, and Blood Institute (NHLBI) at the National Institutes of Health. He is also the NHLBI lead and coordinator of the JNC Blood Pressure Guideline Program and co-lead of NHLBI's Guideline Implementation Work Group. His work at NHLBI focuses mainly on translating research into clinical practice through development, dissemination, and implementation of clinical guidelines and other knowledge management tools. Previous positions include: associate physician and hospitalist at the Brigham and Women's Hospital; associate chief of staff, director of Clinical Informatics, and clinical faculty on the inpatient and outpatient medical services at the Washington, DC Veterans Affairs Medical Center; and senior advisor for Clinical Informatics at the Agency for Healthcare Research and Quality. Dr. Ortiz has also held academic faculty appointments at the Johns Hopkins School of Medicine, Harvard Medical School, George Washington University School of Medicine, and the University of California San Diego School of Medicine.

Puneet Sahni, MD, is currently serving as the project director of the Health Resources Services Administration (HRSA) knowledge management contract focusing on Knowledge Management and Clinical Data Reporting. Dr. Sahni has been involved with the HRSA technology solutions supported by CSI since their inception. Dr. Sahni's medical training and training in medical informatics brings a unique skill set supporting the HRSA programs. This skill set is of particular value in helping to guide the continued adaptation and refinement of the reporting tools as well as being able to reflect the program support needs of those practitioners in the field. Dr. Sahni was historical lead in supporting the Health Disparities Collaboratives (including being the interface with all of the Information System Specialists in the field nationally); the Organ Transplantation Program; the Patient Safety and Pharmacy Collaborative; the SHAP program; the Unified Health Communications portal, and the Office of Rural Health Policy Collaborative. Dr. Sahni's area of expertise is quality improvement in health care settings by focusing on clinical information systems and clinical data.

Thomas Sequist, MD, MPH, is an assistant professor of Medicine and Health Care Policy at Harvard Medical School and Brigham and Women's Hospital. He currently practices general internal medicine at Harvard Vanguard Medical Associates, the largest multispecialty physician group practice in Massachusetts. Dr. Sequist's research agenda focuses on three areas: Native American health care, ambulatory quality improvement strategies, and the intersection between quality of care and health disparities. He has worked to implement Federally funded randomized quality improvement trials in the outpatient setting, and also works closely with the leadership of the Indian Health Service to understand methods of improving Native American health care.

Robert Star, MD, is the director of the Division of Kidney, Urologic, and Hematologic Diseases at the National Institute of Diabetes and Digestive and Kidney Diseases (NIDDK) at the National Institutes of Health (NIH). He is also a senior investigator and chief of the Renal Diagnostics and Therapeutics Unit at the NIDDK. Dr. Star was a postdoctoral fellow at NIH in the mid-1980s before joining the faculty of the University of Texas Southwestern Medical Center in Dallas. In 1999, he returned to NIH as a senior scientific advisor for kidney disease and to run a laboratory studying acute kidney injury. In 2002, he became senior advisor for clinical research in the NIH Office of Science Policy and Planning. There, he worked on the NIH Roadmap for Medical Research initiatives to re-engineer the clinical research enterprise.

The Roadmap aims to stimulate research and develop research resources for cross-cutting large and complex projects with profound potential impact. He also led training and career programs for clinical researchers and helped develop the clinical and translational science awards. Especially interested in translational research, Dr. Star's laboratory focuses on the early identification, prevention, and pre-emption of sepsis and acute kidney injury. His research has produced more than 110 published manuscripts, and he has written eight textbook chapters and holds several patents. Dr. Star graduated summa cum laude in applied mathematics from Harvard College and cum laude from the Harvard Medical School-Massachusetts Institute of Technology Joint Program in Health Sciences and Technology. His internship and residency in internal medicine were performed at Michael Reese Hospital in Chicago. In addition, Dr. Star has received honorary awards and research support from the NIH, U.S. Food and Drug Administration, biotech industry, and the prestigious Young Investigator Award recognizing excellence in nephrology research, jointly awarded by the American Society of Nephrology and the American Heart Association.

David Stevens, MD, is an associate medical officer and director of the Quality Center at the National Association of Community Health Centers (NACHC). Dr. Stevens directs NACHC's clinical quality activities including the quality center, medical home, pay for performance, and quality-related research activities. He also works with primary care associations to foster clinical quality capacity-building, coordination, and alignment efforts. He is also a research professor at The George Washington University School of Public Health and Health Services, Department of Health Policy. Dr. Stevens served as senior medical expert for Quality Improvement at the Agency for Healthcare Research and Quality from 2003 until his appointment at NACHC. He was also acting chief of the Clinical Quality and Professional Management Branch of the Bureau of Primary Health Care (BPHC) and director of Clinical Management and Professional Management and chief medical officer of the Division of Community and Migrant Health. Dr. Stevens holds a MD from The George Washington University in Washington, DC, and completed his residency at Montefiore Hospital and Medical Center in the Bronx, NY.

Katherine Tuttle, MD, is the medical and scientific director of Providence Medical Research Center, Sacred Heart Medical Center in Spokane, WA, and a clinical professor of Medicine in the Nephrology Division at the University of Washington School of Medicine. Her research interests are in the areas of diabetic kidney disease, hypertension, renal vascular disease, and nutrition. She co-chairs the National Kidney Foundation's KDOQI Workgroup for Diabetes and Chronic Kidney Disease and chairs the Healthcare Professional Workgroup for the National Diabetes Education Program.

Desmond Williams, MD, PhD, is the associate branch chief and a medical epidemiologist at the epidemiology and statistics branch of the Centers for Disease Control and Prevention's Division of Diabetes Translation. In this capacity he works closely with the branch chief to oversee the day to day operations and guides the scientific agenda of the branch. Dr. Williams is also the lead of the Chronic Kidney Disease Initiative. This program works with Federal and non-Federal partners to develop comprehensive public health strategies to prevent or delay the development of kidney disease as well as promote early recognition and treatment to delay the progression to serious complications, including cardiovascular disease, end-stage renal disease, or death. Dr. Williams has several years of experience in chronic disease epidemiology and has worked extensively in adult and childhood diabetes, obesity, cardiovascular disease, and childhood cancer. He is an editor of "Diabetes Public Health: From Data to Policy," to be published in 2010 by Oxford University Press.

Sharon Wyatt, PhD, teaches in the PhD and Doctor of Nursing Practice programs at the University of Mississippi and maintains an active clinical practice and research program. Her focus has been on cardiovascular health disparities and innovative community-driven solutions to overcoming disparities using multiple qualitative and quantitative research methods. She is the principle investigator (PI) for the National Children's Study Hinds County Study Center and served as the director and co-PI of the Examination Center of the landmark Jackson Heart Study (JHS), the paramount national study to identify reasons for cardiovascular disease (CVD) disparities in African Americans for its first decade. She has translated findings from the JHS into novel community-driven approaches to health disparities in the Mississippi Delta. Her interdisciplinary approach and commitment to health equality resulted in appointment as the co-chair of the Governor's Task Force for the Prevention of CVD, where she leads the health policy development and implementation of Mississippi's State Plan to reduce disparities. She also holds an endowed chair as a Harriet G. Williamson Professor of Nephrology Nursing.

