

**National Kidney Disease Education Program (NKDEP)  
National Institute of Diabetes and Digestive and Kidney Disease (NIDDK), National  
Institute of Health (NIH)**

**Kidney Interagency Coordinating Committee (KICC) Meeting**  
March 2, 2012, Natcher Conference Center

**Meeting Participants and Summary**

**Barbara Bartman, MD, MPH**

Medical Officer, Center for Outcomes and Evidence  
*Agency for Healthcare Research and Quality*

**Ann Bullock, MD**

Clinical Consultant  
*Indian Health Service*

**Matthew Burke, MD**

Senior Clinical Advisor, Office of Quality and Data  
Bureau of Primary Health Care  
*Health Resources and Services Administration*

**Christine Chang, MD, MPH**

Medical Officer, Center for Outcomes and Evidence  
*Agency for Healthcare Research and Quality*

**Susan Crowley, MD, FASN**

National Program Director for Kidney Disease &  
Dialysis  
*Veterans Health Administration*

**Daniel Farmer**

Stakeholder Engagement Group, Center for Medicare  
and Medicaid Innovation  
*Centers for Medicare & Medicaid Services*

**Michael Flessner, MD, PhD**

Senior Scientific Officer, Division of Kidney,  
Urologic, and Hematologic Diseases  
*National Institute of Diabetes and Digestive and  
Kidney Diseases, NIH*

**Dan Garver, PhD**

Senior Writer  
*National Kidney and Urologic Diseases Information  
Clearinghouse, NIH*

**Gregory Germino, MD**

Deputy Director  
*National Institute of Diabetes and Digestive and  
Kidney Diseases, NIH*

**Mary Harris**

Deputy Director, Office of Communications & Public  
Liaison  
*National Institute of Diabetes and Digestive and  
Kidney Diseases, NIH*

**Mollie Howerton, PhD, MPH**

Health Insurance Specialist, Population Health  
Models Group  
Center for Medicare and Medicaid Innovation  
*Centers for Medicare & Medicaid Services*

**Denise Joseph**

Program Analyst  
*Office on Women's Health*

**Ziya Kirkali, MD**

Extramural Scientific Program Director, Division of  
Kidney, Urologic, and Hematologic Diseases  
*National Institute of Diabetes and Digestive and  
Kidney Diseases, NIH*

**Bernard Kozlovsky, MD**

Medical Officer, Division of Transplantation  
*Health Resources and Services Administration*

**Siddhartha Mazumdar, PhD**  
Social Science Research Analyst, Center for  
Medicare and Medicaid Innovation  
*Centers for Medicare and Medicaid Services*

**Kevin McBryde, MD**  
Program Director, Office of Minority Health  
Research Coordination  
*National Institute of Diabetes and Digestive and  
Kidney Diseases, NIH*

**David Miller, MD, MPH**  
Health Science Policy Analyst  
*National Institute of Diabetes and Digestive and  
Kidney Diseases, NIH*

**Ernest Moy, MD, MPH**  
Medical Officer, Center for Quality Improvement and  
Patient Safety  
*Agency for Healthcare Research and Quality*

**Andrew Narva, MD, FACP**  
Director, National Kidney Disease Education  
Program  
*National Institute of Diabetes and Digestive and  
Kidney Diseases, NIH*

**Eileen Newman, MS, RD**  
Associate Director, National Kidney Disease  
Education Program  
*National Institute of Diabetes and Digestive and  
Kidney Diseases, NIH*

**Nancy Nielsen, MD, PhD**  
Senior Advisor, Center for Medicare and Medicaid  
Innovations  
*Centers for Medicare and Medicaid Services*

**James Oliver III, MD, PhD**  
Colonel, Medical Corps, U.S. Army  
Nephrology Service, Walter Reed Army Medical  
Center  
Nephrology Consultant to the Office of The Surgeon  
General  
Associate Professor and Director, Nephrology  
Division, USUHS

**Eduardo Ortiz, MD, MPH**  
Senior Medical Officer, Division for the Application  
of Research Discoveries  
Senior Advisor, Center for Biomedical Informatics  
*National Heart, Lung, and Blood Institute, NIH*

**Diane Reid, MD**  
Medical Officer, Division of Heart and Vascular  
Diseases  
*National Heart, Lung, and Blood Institute, NIH*

**Nilka Ríos Burrows, MT, MPH**  
Epidemiologist, Division of Diabetes Translation  
*Centers for Disease Control and Prevention*

**James Smith, MD, MS**  
Medical Officer, Division of Metabolism &  
Endocrinology Products  
*Food and Drug Administration/CDER*

**Kimberly Smith, MD, MS**  
Medical Officer, Division of Quality Improvement  
Policy for Chronic and Ambulatory Care  
Quality Improvement Group, Office of Clinical  
Standards and Quality  
*Centers for Medicare & Medicaid Services*

**Rob Star, MD**  
Director, Division of Kidney, Urologic, &  
Hematologic Diseases  
*National Institute of Diabetes and Digestive and  
Kidney Diseases, NIH*

**Aliza Thompson, MD**  
Medical Officer  
*Food and Drug Administration*

**Nancy Xu, MD**  
Medical Officer, Division of Cardiovascular and  
Renal Products  
Center for Drug Evaluation and Research  
*U.S. Food and Drug Administration*

**Susan Zieman, MD, PhD**  
Medical Officer, Geriatrics Branch  
Division of Geriatrics and Clinical Gerontology  
*National Institute on Aging*

## **I. Welcome and Introductions**

Andrew Narva, MD, FACP

Dr. Narva welcomed committee members and thanked them for their participation.

The committee was created in 1987 by Congress. The goal of the committee is to encourage cooperation, communication, and collaboration among all Federal agencies involved in kidney research and other kidney-related activities.

During the fall 2011 meeting which focused on evidence-based care, participants identified the need to explore existing research gaps that must be addressed in order to reduce the burden of kidney disease in the United States.

## **II. Federal Chronic Kidney Disease Research Coordination: Planning for the Future**

Robert Star, MD

There is a range of research-related activities required to bring effective treatments and interventions to chronic kidney disease (CKD)/End-Stage Renal Disease (ESRD) patients. These include:

- Discovery;
- Refinement/translation;
- Clinical trials;
- Translation to practice; and
- Translation to the population.

Various Federal agencies and other stakeholders play different roles in supporting these activities. For example, the Agency for Healthcare Research and Quality (AHRQ) focuses on the translation of research findings to practice. The Centers for Disease Control and Prevention (CDC) focuses on the translation of research findings to specific populations and subpopulations. While the roles of the various Federal agencies and stakeholders are fairly well defined, it is necessary to better coordinate activities across the research and translation spectrum.

### **Discussion**

Meeting participants engaged in a discussion on current research gaps and how to promote more collaboration across the research spectrum.

### ***Research Gaps***

- Standardize data definitions for key CKD/ESRD variables
- Develop simple comparative effectiveness research (CER)/ Patient-Centered Outcomes Research Institute (PCORI) studies to improve dialysis care (e.g., cramping, fragility, infection control)
- Economic models/cost savings (e.g., dialysis organization could serve as a setting for this type of research)
- Prevention/risk factors
  - How to identify patients at risk of progression (what are the indicators?)

- How to target interventions
- CKD in aging populations (possible partners: American Geriatric Society, NIH Work Group on geriatrics)
  - Protocols for evaluating CKD patients for cognition and functional abilities
  - How to define CKD in this population
  - Appropriate management
- Patient-based outcomes (i.e., what is the best care for a patient)
  - Focus groups of patients to identify their concerns
  - Patient surveys
- Clearer endpoints and treatment targets (e.g., targeted goals for blood pressure)
  - Tie to performance measures
- Patient outcomes based on care settings
- Issues related to the care of complex patients
- Safe and effective use of drugs
- Treatment adherence issues
- Health disparities and CKD
- Role of home dialysis
- Shared decision making (providers, patients, families)
- Role of peer educators in improving care

***Additional Partners***

- VA/DOD
- Community health centers (including health center control networks and the Beacon Health Center Collaboration)

***Other Considerations***

- Linking to Healthy People 2020
- Impact of Affordable Care Act
- Use of EHRs for research
- Involving provider community on potential changes in payment structure

**Collaboration: Key Outcomes**

- Identify existing tools that are currently underutilized (e.g., cognition and function screening tools for elderly patients)
- Develop standard terminology
- Develop validated, patient-reported outcomes (need to partner with FDA, industry)
- Conduct joint research/projects (across agencies, public/private)

**III. Center for Medicare and Medicaid Innovation: End-Stage Renal Disease Initiative**  
Daniel Farmer

The CMS Innovation Center fosters health care transformation by finding new ways to pay for and deliver care that improves treatment outcomes and health while lowering costs. The Center identifies, develops, supports, and evaluates innovative models of payment and care service delivery for Medicare, Medicaid, and CHIP beneficiaries using an open, transparent, and competitive process. Established by the Affordable Care Act, priorities for the Center include:

- Improve coordination of care;
- Improve the health of the targeted population;
- Lower costs to Medicare through improved care; and

- Test the effectiveness of models in accomplishing these goals.

**Discussion**

The discussion focused on care for beneficiaries with CKD and ESRD.

**Adjournment**

Dr. Narva closed the meeting, thanking participants for their participation.