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

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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)
  o Protocols for evaluating CKD patients for cognition and functional abilities
  o How to define CKD in this population
  o Appropriate management
• Patient-based outcomes (i.e., what is the best care for a patient)
  o Focus groups of patients to identify their concerns
  o Patient surveys
• Clearer endpoints and treatment targets (e.g., targeted goals for blood pressure)
  o 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.