National Kidney Disease Education Program (NKDEP)
National Institute of Diabetes and Digestive and Kidney Diseases
National Institutes of Health

Coordinating Panel Meeting

October 22, 2007
Marriott Bethesda Suites
Bethesda, MD

Meeting Summary

NKDEP Coordinating Panel

Karen Basinger, MS, RD, LN
Henry Brehm
Ann Bullock*, MD
Ahmed Calvo*, MD, MPH, FAAFP
Anne Camp, MD
Mary Teresa Casey, RD, LD
Jeanne Charleston, BSN, RN
Ann Compton, MSN, FNP-C, CNN
Victoria Dent, BSW
Kristina Ernst, RN, CDE
Mildred Fennal*, PhD, RN, CNS, CCRN
Deborah Fillman*, RD, LD, MS, CDE
Eugene Freund*, MD, MSPH
Robinson Fulwood, PhD, MSPH
Joanne Gallivan, MS, RD
Richard Goldman*, MD
Mary Jo Goolsby, EdD, MSN, NP-C
Lois Hill, MS, RD, LD, CSR
Frederick Kaskel, MD, PhD
M. Sue Kirkman, MD
Theresa Kuracina*, MS, RD, CDE
Daniel Larson, BS
Derrick Latos, MD, MACP
Janice Lea, MD
Stephanie Mahooty, BSN, RN, CNN
William McClellan*, MD, MPH
Keith Norris, MD
Carlos Palant*, MD
Margery Perry*
Dori Schatell, MS
Eric Simon, MD
Dale Singer, MHA
Marisa Soto, PharmD, CDE
Michael Spigler, CHES

David Stevens, MD

Joseph Vassalotti, MD, FASN

Roberta Wager*, RN, MSN

Bessie Young*, MD, MPH

*Unable to attend

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Andrew Narva, MD, FACP
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I. Welcome and Introductions

Andrew Narva opened the meeting by welcoming the participants and inviting them to introduce themselves. Dr. Narva spoke about the important role Coordinating Panel (CP) members play in helping NKDEP accomplish its goals. He reviewed the evolution of the group over the last year to comprise individual experts rather than organizational representatives. He outlined the goals for the meeting, which were to: 1) help CP members become more familiar with the

chronic care model (CCM) and how it can help guide the NKDEP; and 2) have CP members provide ideas and feedback to help shape future NKDEP efforts.

II. The Chronic Care Model: What Does It Mean for CKD?

Dr. Narva presented an overview of the CCM and how it can guide NKDEP's efforts to improve diagnosis and treatment of chronic kidney disease (CKD). He reviewed the burden of CKD in the United States and the availability of diagnostic tools and treatment approaches that are often underutilized. He explained that health care professionals could do more to manage CKD patients in the primary care setting but that many clinicians may not do so because they feel unprepared or they feel that a referral is necessary. To address these issues, NKDEP is focusing on helping providers understand CKD and its' management within the treatment of hypertension and diabetes.

Dr. Narva reviewed the history of the CCM, its elements, and the importance of having informed, activated patients and a prepared, proactive health care team to improve CKD outcomes. He explained how the CCM can be a useful paradigm for NKDEP's work; it can help improve NKDEP's ability to communicate about its goals and activities, identify priority areas, and measure effectiveness. He noted the Indian Health Service (IHS) as a relevant example because it has shown evidence of a decline in end-stage renal disease (ESRD) incidence using strategies that are consistent with the CCM.

Dr. Narva stressed that CKD *is* part of primary care. NKDEP, therefore, is working to make it easier for primary care professionals to detect and treat CKD and to educate their patients. The program has started work toward this goal with a variety of activities. Dr. Narva highlighted some NKDEP activities and how they align with the key components of the CCM, including the development of a patient education fact sheet about GFR and collaboration with the nutrition community. He closed his presentation by inviting the group to provide feedback on the relevance and appropriateness of the CCM to NKDEP's activities and to suggest ideas for additional activities.

Dr. Narva's presentation slides, including a diagram of the CCM, can be found on the NKDEP website at www.nkdep.nih.gov/about/panel.htm#meeting.

III. Remarks on Dr. Narva's Presentation

David Stevens from the Agency for Healthcare Research and Quality spoke in greater depth about the CCM, which is being adopted by health plans, Federal agencies, state programs, and others. He focused on two aspects of the model that make it useful: it takes a systems approach toward change, which is easier to sustain; and it provides a structure to help identify and address issues common across chronic conditions.

Dr. Stevens reviewed the key challenges and opportunities for using the CCM, including ensuring activities line up with financial incentives, measurement challenges with multiple interventions, and the large burden of chronic disease. He emphasized that in order to be successfully applied, the CCM needs support from providers, patients, the community, and leaders. He closed by discussing the barriers to and opportunities for using the CCM in the current and future health care environment.

IV. Moderated Group Discussion

Michael Briggs moderated a discussion about NKDEP's proposed use of the CCM as a guiding paradigm. The goal of the discussion was to take advantage of having this group of experts together to talk about the benefits or disadvantages of the model and what can be done next. The group acknowledged the usefulness of the model and identified several issues and opportunities with it. Below is an overview of the discussion by topic.

DISCUSSION TOPIC 1: Ways to teach providers about the benefits of the CCM and encourage them to take a systems/population approach.

- Rick Latos raised the challenge of engaging physicians who typically think in terms of a one-patient model.
- Anne Camp cited her positive experience with the Health Disparities Collaborative in the community health center (CHC) setting. She said that providers were receptive to the idea of using the CCM for chronic conditions and the model was successful at forging systems change.
- Dr. Latos said physician practices would have more difficulty adopting the CCM because they are not already in a system like the CHCs. Lois Hill echoed the concern for dietitians, who also may not work in a structured health system.
- Kris Ernst pointed out that the American College of Physicians (ACP) and American Association of Diabetes Educators are promoting a manual on the CCM for diabetes, which recommends that providers track diabetes patients as a first step in thinking about populations. They also offer trainings on how to set up the CCM in a practice.
- Dr. Stevens mentioned that American Association of Family Practitioners and ACP have pilot projects that showcase "practices of the future." There could be state-level opportunities as well, or small practices could work together.
- Rob Fulwood explained how National Heart, Lung, and Blood Institute (NHLBI) partnered with Health Resources and Services Administration to create a demonstration training center at a CHC that trains other health centers on chronic disease.
- Dori Schatell offered Fistula First as a data- and quality-driven model that helps pull pieces together under one strategy.
- Another idea proposed was to teach the CCM to medical students.

DISCUSSION TOPIC 2: Benefits of the CCM for approaching CKD.

- Ms. Schatell stated that chronic disease patients are currently being cared for under an acute care model, which is not effective.
- Keith Norris stressed the importance of structuring systems so changes are seamless for providers who are dealing with competing requests for additions to the primary care visit.
- Since CKD is an extended part of diabetes and high blood pressure care, imbedding evidence-based guidelines of what providers should be doing could make it less burdensome. The electronic health record and lab report can provide some starting information on what to do next. Dr. Latos reiterated that automatic results from a screening panel would be very helpful.
- In addition, since patients often have several chronic diseases, providers need to be looking at kidney function anyway for patient safety issues related to medications.

- Karen Basinger pointed out that she has been using the CCM approach as a renal dietitian without realizing it. She started with diabetes and has moved into kidney disease, and now physicians refer to her for nutrition counseling more often.

DISCUSSION TOPIC 3: Importance of informed, activated patients—a key component of the CCM—to drive physician practices toward earlier diagnosis and intervention.

- Ms. Schatell spoke of engaging patients by using adult education principles, improving health literacy, and identifying ways to overcome patient fears.
- Dr. Norris stressed the need to integrate chronic disease education and improve health literacy both in the workplace and the school system in order to change the prevailing mindset toward health. For example, health education in schools tends to focus on discrete health behaviors rather than the overarching concept of chronic disease.
- Daniel Larson said the message would be most powerful coming from celebrity spokespersons who are culturally relevant to audiences and can generate awareness through media coverage.
- Joseph Vassalotti stressed the importance of focusing on those with the key risk factors to impact earlier diagnosis.

DISCUSSION TOPIC 4: Patient education and messaging.

- Through a study with diabetes educators, Ms. Schatell found that kidney complications were not mentioned because the educators were primarily teaching diabetes basics and did not have time to focus on complications.
- Dr. Stevens emphasized that it would be helpful to combine the multiple "know your numbers" messages into one campaign and add a kidney number. Similarly, adding GFR and microalbuminuria screening to diabetes quality measures would be helpful, as it could then drive a Healthcare Effectiveness Data and Information Set (HEDIS) measure and pay-for-performance goals.
- Patients may need help sorting through all the health information they get, especially if they do not have insurance and must prioritize their care based on the results they receive at health fairs. Information cannot be only web based, since many patients do not have access to the Internet.

DISCUSSION TOPIC 5: Need for a prepared, collaborative health care team—another component of the CCM—that fully utilizes the skills and training of each health care professional involved.

- Marisa Soto spoke about the importance of educating health professionals about the benefits of working with a multidisciplinary team. This could occur both by students participating in team-based training and by professionals promoting best practices and guidelines outside of their disciplines (e.g., through publishing).
- Adding GFR to lab reports can help activate other providers on the team by increasing referrals to dietitians and pharmacists.

DISCUSSION TOPIC 6: NKDEP's role in promoting primary care of CKD.

- Dr. Narva said that NKDEP's goal is to educate health care professionals to consider CKD to be part of primary care, and to provide simple tools to help them do it. He agreed with the

need to pool resources and work together more on these issues; for NKDEP, for instance, that means working more with the National Diabetes Education Program and NHLBI.

- Janice Lea added that NKDEP has to be sure to foster a continuous educational relationship with providers and the community rather than a one-time promotion of a tool.
- Another role suggested for NKDEP is to work through provider organizations to educate providers about CKD staging (e.g., by creating algorithms, protocols).
- In addition, NKDEP could help foster collaboration between primary care providers and nephrologists by borrowing a model from HIV care where a specialist is paid to review cases a few times a month. Dr. Narva has used that model at IHS and suggested that nephrologists may be interested in it.

DISCUSSION TOPIC 7: Relationship between primary care providers and nephrologists.

- While it was pointed out that primary care providers are not scared to lose patients once they refer to nephrologists, Marva Moxey-Mims said that patients can feel overwhelmed and burdened by having to see both doctors.
- Dr. Vassalotti stated that the majority of care needs to be with primary care as there are too many patients for nephrologists to treat. Rather than viewing it as separate groups, he sees the two types of providers working together since there is so much to be done.
- The group also talked about the importance of the various providers conveying a consistent message.

V. Recognition of Associate Director

Dr. Narva recognized the contributions of Elisa Gladstone, who recently left her position as NKDEP's Associate Director. He thanked her for her service to the program over the past four and a half years, presented her with a certificate of recognition, and wished her well in her new position as communications director for the National Institute of Nursing Research.

VI. NKDEP 2007 Highlights

Several NKDEP staff members presented highlights of the program's activities in 2007. Anna Zawislanski reported on the status of the NKDEP **website redesign** project to expand website content and improve organization. She outlined NKDEP's efforts to help coordinate Federal partners through the **Kidney Interagency Coordinating Committee**.

Highlighting activities related to health care professional outreach, Ms. Zawislanski presented on the development of a **fact sheet for diabetes educators** on UACR and GFR. Karen Toll Goldstein outlined the development and testing of a **patient education tool on GFR** for primary care providers, as well as collaboration with nutrition professionals on an article about improving nutrition care for early CKD patients.

Ms. Toll Goldstein reviewed public education materials and programming for African Americans, including the **Family Reunion Initiative** and a new educational brochure.

Nancy Accetta discussed NKDEP's outreach to laboratory professionals about **GFR reporting**, including results of a recent NKDEP study on GFR reporting in the United States. She closed the presentation by summarizing NKDEP's Laboratory Working Group's efforts with **creatinine and urine albumin standardization.**

Comments following the presentation included:

- Dr. Norris pointed to the importance of defining a common terminology around urine albumin testing when talking to patients, which Dr. Narva acknowledged would be part of the urine albumin standardization efforts.
- Dr. Vassalotti congratulated NKDEP on the work it has done to raise awareness, and asked when creatinine standardization would be completed. Dr. Narva and Ms. Accetta answered that it should be completed within the next two years.

VII. Role of Sex Hormones in the Pathophysiology of Diabetic Renal Disease

Christine Maric presented on the differences in rates of diabetes and kidney disease between men and women, and the impact of sex hormones on these conditions. She reviewed the results of several studies that conclude that diabetes is associated with an imbalance in hormone levels, with estradiol being protective against diabetes and kidney disease. Testosterone has the opposite effect with hypertension and kidney disease. She explained that selective receptor modulators can help people get the benefits of hormone therapy without harmful side effects.

In response to a question about the differences for type 2 diabetes, Dr. Maric responded that while research for type 2 is just beginning, it seems that the protection is lost.

VIII. The Centers for Disease Control and Prevention's Chronic Kidney Disease Initiative

Ms. Ernst, on behalf of the CDC's Division of Diabetes Translation, presented on the recent legislation awarding CDC $1.8 million for a kidney disease surveillance, epidemiology, and health outcomes program, which led to the Kidney Disease Initiative and the formation of CDC's kidney team. Ms. Ernst reviewed the various initiatives being funded by the legislation, including an expert panel meeting, national surveillance system, demonstration project, and other studies and collaboration with partners. Results from the expert panel meeting (held March 5-6, 2007) should be published in the *American Journal of Kidney Diseases* by the end of the year. She also talked about the Diabetes Prevention and Control Programs' interest in working on CKD, and the state and community resources they can leverage.

When asked about the structure of the initiative, Ms. Ernst explained that it was organized through chronic disease centers. Dr. Stevens asked if GFR could be added to National Health and Nutrition Examination Survey (NHANES) to measure the general population compared to those with key risk factors, and Ms. Ernst answered that this has already been addressed.

IX. Emerging Trends in CKD: USRDS Update

Paul Eggers presented on emerging trends in CKD and ESRD. An article on the prevalence of CKD in the United States using NHANES data will appear shortly in *Journal of the American Medical Association*. The data shows a 30% increase in CKD across all stages from 1988-1994 to 1998-2004, much of it due to increases in diabetes and hypertension. He noted that although the estimated number of people with CKD has increased to 26 million, most stage 3 CKD patients are people over age 70 with no evidence of microalbuminuria. Dr. Eggers reviewed related measures of preventive tests and treatments. ESRD rates continue to remain flat, which may be due to better treatment of CKD, especially among those with diabetes.

Responding to a question about diabetes patients dying before getting to stage 4 or 5 CKD, Dr. Eggers stated that it is a major concern for younger diabetics but he was less sure of how it

impacts those older than 70 with stage 3 CKD. In response to questions about research on other aspects of the data, Dr. Eggers said that they did not check differences by gender and race but have no reason to believe it would differ by race; they also have not looked at trends in children. Dr. Norris asked if the change in census reporting could impact the data. Dr. Eggers said that the Native American category changed the most, but that the information is not the same as what USRDS provides.

X. Chronic Renal Insufficiency Cohort (CRIC) Study

John Kusek gave an overview of the CRIC Study, including its goals, structure, and challenges. The study is looking at the progression of kidney disease over time and trying to identify risk factors for possible intervention. Dr. Kusek reviewed the recruitment goals and cohort composition, and explained that there is a companion Hispanic CRIC Study.

The first phase of the longitudinal study is ending next summer, and planning has begun for Phase II. While data are starting to emerge, the next three to four years should yield important information. One early finding suggests that this population could create a substantial burden from hospitalization over time. He anticipates clinical trials will result from Phase II.

XI. CKiD: Chronic Kidney Disease in Children

Dr. Kaskel presented an overview of the CKiD study, which is looking at CKD progression and effects in children. The study is currently in the third of five years, and is planning renewal for five years. The birth history data shows high rates of kidney disease coming from birth risks and low birth weight. The participants also have high blood pressure, but fewer than half are being treated for it. Dr. Kaskel also noted that family history factors in children are not treated as aggressively as they are in adults. He suggested that the study may indicate a need to change the variables used to measure GFR in children. He reviewed the focus areas for the next phase of CKiD and ancillary studies.

Questions were raised about other factors, such as renal volume, smoker in the home, and high birth weight. Some of the data has been collected but not analyzed yet and some will likely be collected in an ancillary study.

XII. Next Steps and Closing Remarks

Dr. Narva closed the meeting by thanking everyone for coming to and participating in the meeting. He noted that the discussion reflected a consensus that NKDEP should move ahead using the CCM paradigm. NKDEP will solicit help from members as needed, and he thanked them in advance for their contributions in the coming year.