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

Coordinating Panel Meeting

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Bethesda Pooks Hill Marriott
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Meeting Summary

Participants

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American Health Quality Association

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Forum of ESRD Networks

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American Academy of Nurse Practitioners

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I. Welcome and Introductions

Dr. Robert Star opened the meeting by welcoming the Coordinating Panel (CP) members and recognizing their contribution to the growth and success of the National Kidney Disease Education Program (NKDEP). He then introduced Dr. Andrew Narva as the new Director of the NKDEP, highlighting his work on kidney disease for the Indian Health Service. Dr. Star then recognized Ms. Elisa Gladstone for her interim leadership of the program, congratulating her on receiving the Director's Award from the National Institute on Diabetes and Digestive and Kidney Diseases (NIDDK).

II. Goals for the Meeting

Dr. Andrew Narva led the introduction of the meeting participants. He acknowledged the leadership of Dr. Tom Hostetter, NKDEP's previous director, and the contributions of Ms. Gladstone to NKDEP's success. Dr. Narva explained that because the NKDEP is an established program, this is an appropriate time to work toward more active collaboration with CP members. Dr. Narva then outlined the agenda for the rest of the day.

III. Program Update

Ms. Elisa Gladstone presented an overview of the NKDEP, including the reasons why NKDEP was created, the importance of early detection and treatment, and NKDEP's objectives and approach. The NKDEP support staff – Michael Briggs, Karen Toll, Nancy Accetta, and Anna Zawislanski – presented on NKDEP's activities over the past year.

Mr. Briggs highlighted NKDEP's latest materials and outreach efforts. His presentation focused on NKDEP's new brochure for the general public and resources for the at-risk Hispanic population. Ms. Toll emphasized NKDEP's efforts to reach the African-American community through the Family Reunion Initiative and reviewed NKDEP's efforts to reach at-risk family members through the Dialysis Center initiative. Ms. Victoria Dent shared her personal experience with the Family Reunion Health Guide at her own family reunion. Dr. Bill McClellan pointed out that the Family Reunion Initiative might want to target the end-stage renal disease (ESRD) population.

Ms. Accetta explained NKDEP's seminal efforts to standardize creatinine and encourage routine reporting of estimated glomerular filtration rate (eGFR). This presentation generated a robust discussion regarding creatinine, eGFR, and estimating equations. Overall, many participants acknowledged the efforts of the NKDEP in leading the Creatinine Standardization Program (CSP) and thanked Ms. Gladstone for her efforts. Dr. Narva explained GFR in lay terms.

On estimating equations
The group discussed the limitations of GFR estimating equations, and the opportunity for NKDEP to educate the provider community about eGFR. It was pointed out that it is important for eGFR to be considered a diagnostic tool. Dr. McClellan pointed out that the validity issues of the Modification of Diet in Renal Disease (MDRD) Study equation do not affect those with serious kidney disease and that the issue is for those hovering in the area of near-normal kidney function. Dr. Andy Levey is working to validate the MDRD equation in other populations through the NIDDK funded, CKD Epi study. Dr. Patel expressed confusion over the two GFR calculators that appear on the NKDEP website. Ms. Gladstone clarified that one calculator uses the original MDRD equation and the other employs the IDMS-traceable MDRD Study Equation to calculate GFR. NKDEP will work to further differentiate the equations to avoid continued confusion.

On eGFR
Dr. Narva also explained that the implementation of eGFR marks a new way to look at kidney disease. This is a public health intervention—the fact that eGFR has been promoted by the National Institutes of Health is critical.

Dr. Eugene Freund indicated that clinicians do not want eGFRs reported because they "do not know what to do with them." The NKDEP needs to be careful not to raise a question in providers' minds regarding the validity of eGFR.

On creatinine
Dr. Narva pointed out that all measures based on creatinine will be imperfect. Dr. McClellan added that creatinine is ordered as part of the routine metabolic panel.

Following the laboratory discussion, Ms. Zawislanski presented on NKDEP's outreach to health professionals. She also highlighted the latest NKDEP website expansion efforts. Ms. Gladstone described the outcomes of the Evaluation Working Group efforts and highlighted NKDEP collaborations at the State and Federal levels.

Additional comments made during this presentation were:

- Several participants agreed with Ms. Gladstone that her slide, which graphically depicts how treatment delays progression to ESRD, communicates a very powerful and important message. NKDEP should look for opportunities to package and disseminate this information in creative ways.
- There was discussion around the importance of developing a Heath Plan Employer Data and Information Set (HEDIS) measure based on eGFR.

IV. NKDEP Program: Looking Ahead

Dr. Narva opened this presentation by sharing some of his experiences working with the American Indian population while at the Indian Health Service (IHS), and outlining lessons he learned that are relevant to NKDEP. IHS was the first national care provider to implement GFR. He noted that NKDEP will be expanding its scope to address broader range of treatment issues and presented NKDEP's 2007-2008 objectives. Those objectives are to: help primary care providers better assess and treat chronic kidney disease (CKD), help health professionals better

educate patients about CKD, improve diagnostic tools used to assess kidney function, and improve coordination of the Federal response to CKD.

On interpreting data
Dr. Latos asked whether the reported decrease in diabetic ESRD may be due to an increase in mortality prior to initiation of renal replacement therapy. Dr. Narva acknowledged that this is an important question. Dr. McClellan added that the increase in average life expectancy in the past decade makes it much less likely that the change is due to a decrease in ESRD incidence.

On primary care
Dr. Narva explained that his goal is to make primary care providers more comfortable with renal care, not to increase the number of renal clinics or renal nutritionists. Our challenge is to convince primary care providers (PCPs) that CKD is part of primary care and help them identify who is at greatest risk. Messages to providers cannot be too simple—most physicians are not comfortable with eGFR, which is an obvious barrier to them explaining it to their patients.

Dr. Patel explained that four years ago, the Veterans Administration developed Department of Defense guidelines for primary care, which included stages of CKD and GFR. He added that they have been field tested, and to date, they are the best evidence-based guidelines. They are available on VA's website in the kidney section. He also commented that the best way to make changes like this is through electronic medical records (EMR).

On measurements and outcomes
Measuring outcomes is a great way to change provider care. Dr. Narva said that CKD is an area where outcomes can be easily measured. Every provider wants to be above average. Once they know they are being measured, they will improve care.

On Federal coordination
Dr. Narva pointed out that the Center for Medicare & Medicaid Services (CMS) is the biggest player in the kidney field. The Centers for Disease Control and Prevention (CDC) is developing a CKD surveillance program and a number of other agencies have programs as well. In a time of limited resources, we want to prevent duplication of efforts. Dr. Ahmed Calvo spoke about possible opportunities using EMR, which currently helps the Health Resources and Services Administration (HRSA) with measurement. He would like to follow up on the idea of combining registries. By connecting the Federal, State, and local levels, HRSA has improved cancer screening. He pointed out that community heath centers use the Resource and Patient Management System (RPMS).

V. Lunch Presentation: Emerging Trends in CKD

Dr. Paul Eggers presented on emerging trends in CKD, ESRD, and acute kidney injury (AKI). He used data to explain the prevalence of CKD and its possible increase and pointed out that progression is not well understood. For example, CKD rates for blacks and whites are the same. However, ESRD rate for blacks is four times as high as for whites. We do not understand the reason for this difference. The interaction of CKD and AKI has yet to be characterized.

Overall, ESRD incidence rates have stabilized since 2000. There is some reason to believe this may be due to better treatment of CKD, particularly among persons with diabetes. Every ESRD patient costs Medicare approximately $65,000 per year; mean life expectancy for ESRD patients is four years. Therefore, even a small decrease in ESRD incidence makes a big economic impact.

On blood pressure
Dr. Patel asked why blood pressure was not included in the presentation. Dr. Eggers explained that there is no billing code for testing blood pressure, although anti-hypertensive drugs will be available under new Medicare benefit, which might provide an opportunity for measurement.

On observational studies
Dr. McClellan explained that there is no proforma evidence that the changes being implemented are making an improvement in outcomes, which is a problem with observational data. Clinicians like to see evidence but they have to accept this kind of data because clinical trials do not provide external evidence.

VI. Selected Presentations

In preparation for this session, NKDEP selected eight organizations (to reflect a range of CP members) and asked their representatives to make short presentations on how their organization could collaborate with NKDEP.

American Association of Diabetes Educators (AADE)
Ms. Deborah Fillman explained that the AADE is made up of 12,000 multi-disciplinary members, most of whom are nurses and dietitians. There are one hundred chapters across the U.S. and its territories. Four areas for AADE and NKDEP collaboration are: behavior change, outcomes, public health issues, and cost. Her response to "how can we work together" is how can we not. Specifically, publications and health professional tools present collaboration opportunities.

On young people
Dr. Veronica Clarke-Tasker asked if AADE has considered working with young people to better reach those who are being diagnosed with Type 2 diabetes at a younger age. Ms. Fillman agreed that this is very important and represents a major shift in diabetes education. The average diabetes educator is a middle-aged woman. AADE is working on getting younger people to serve as mentors. Ms. Accetta pointed out the importance of considering schools as a diabetes education setting.

American Association of Kidney Patients (AAKP)
Mr. Benjamin Kirby discussed the Kidney Beginnings program which includes presentations on CKD. AAKP is always looking for information for their presentations, which they give throughout the country. They are also looking for articles for their magazines and four e-newsletters. Mr. Kirby pointed out that the November issue of *Kidney Beginnings* features an article by Dr. Narva.

AAKP is also working toward improved coordination with Federal response and is interested in including Federal activities in their policy newsletter.

He explained that AAKP recently revamped their website, which has a new patient feature called *My Health.* This feature provides a place for patients to track their appointments, test results and gather information. There are 700 registered users already. CKD is the most common modality in use.

American College of Physicians (ACP)
Dr. Latos explained that the ACP membership is extremely diverse, representing all types of doctors. The ACP Board of Reagents adopted a resolution urging the College to make CKD a priority.

With Andy Levey as the co-editor, the *Annals of Internal Medicine* has been focusing on CKD (at least three recent publications on CKD). The monthly newsletter, the *Observer*, presents an opportunity to reach physicians with CKD messages. The October edition, for example, features a cover story on CKD.

How can NKDEP get involved with ACP to get on annual session programs? Planning for annual meeting starts three to five years ahead of time. ACP represents membership through its Board of Governors. Each chapter has a governor, who promotes membership and policy. Governors hold annual meetings in their locales—they determine what will be on each program at chapter meetings. These annual meetings can be an opportunity for NKDEP. Dr. Latos will speak to the Board of Governors about having Dr. Narva speak.

On the ABIM
Dr. McClellan asked how much influence ACP has over the American Board of Internal Medicine (ABIM). Dr. Latos responded that there is an "arms length" between ACP and ABIM. There is very little happening in Board Certification with CKD. NKDEP could have some discussion about CKD with those who write exams. "I hate to be teaching to the test, but that's a great way to learn," said Dr. Latos.

On lack of exposure to transplant patients
Dr. Golconda commented on the fact that medical students are not exposed to kidney transplant patients, and therefore, providers do not know how to treat them. Dr. Latos agreed and said he would ask about including transplant care to the annual meeting agenda.

On decision support tools
Dr. Latos pointed out that ACP has a decision support tool on the web for general internists as part of its Practice Management Center. Dr. McClellan asked if it works for referral for CKD, and Dr. Latos responded that it could be more useful for clinical support rather than just office management support.

Dr. Lori Orlando explained that she helped test the Consult Letter Template with RPA (developed with NKDEP), which serves as a communication tool between nephrologists and PCPs. They are currently working to make the RPA toolkit electronic. They also are testing a decision support tool that will be more appropriate in a primary care setting.

Dr. Narva added that it's important that tools clarify the sequence of what the PCP does before referring to a nephrologist. Specifically, it is important that the generalist do the basic workup *before* referring to the nephrologist.

American Dietetic Association (ADA)
Ms. Karen Basinger, who is in the Renal Practice Group of ADA, explained that dietitians feel underutilized. They are looking to NKDEP to help promote dietitians and would like to be more involved in slowing progression to ESRD.

Ms. Basinger pointed out that ADA's quarterly newsletter is a great opportunity to educate patients and members. At its annual meetings, ADA can add speakers to educate the entire membership about CKD. It is interested in continuing to field test NKDEP brochures and other publications and also is available to help with writing.

Dr. Narva asked if ADA needs a module to help general dietitians get up-to-speed on working with renal patients. Ms. Basinger said the area networks and area coordinators answer questions that arise on this issue.

On the Medicare benefit

Dr. Leland Garrett raised the issue of the difficulty of getting reimbursed by Medicare for dietitian services. Mr. Dolph Chianchiano added that the Medicare benefit is underutilized. Ms. Basinger explained that the key is to have a very experienced billing professional who knows how to get reimbursed.

American Health Quality Association (AHQA)

Dr. Clare Bradley addressed the group from the QIO perspective and explained that CMS directs the AHQA in its activities. AHQA works in different settings that could be in sync with NKDEP's efforts. One of its goals is to increase EHR in physician offices and to improve care. This would enable physician offices to communicate with other settings, such as hospitals and labs.

Another important area is health disparities and cultural competency, e.g., ensuring that information is presented in a linguistically appropriate manner.

The AHQA works with many CP member organizations. Its current scope of work will end in 2008. Dr. McClellan pointed out that microalbuminuria is not included as a quality indicator. Dr. Freund said CMS is considering many issues for the 9th scope of work.

Association of Clinicians for the Underserved (ACU)

Ms. Marisa Soto explained that the ACU is made up of 8,000 members and over 900 organizations, with 18 professional disciplines. Many of the organizations include promotoras and lay health educators. One thing that is unique about the ACU is that their Board of Directors includes students as well as community members.

The ACU strives to offer low-literacy and culturally appropriate materials and training for promotoras, lay educators, and faith-based organizations. Other goals of ACU are to provide web-based support for clinicians and maintain awareness that success requires partnerships with clinicians, patients, and the community.

Ms. Soto explained her role at the El Rio Community Health Center, where she and another colleague, who are pharmacists, are responsible for chronic disease management and prescribe medicine. She explained that El Rio built eGFR into their database because their labs currently do not provide eGFR.

Forum of ESRD Networks

Dr. Leland Garrett said that the networks and the Forum are looking for ways to focus on CKD stages 3 and 4 outside of their CMS contract. He listed the following potential collaboration activities with NKDEP relates to CKD stages 3 and 4:

- Add (or link to) Fistula First materials on NKDEP website
- Prepare a joint brochure for health professionals on fistula preparation
- Add comments on "saving an arm" to the CKD Overview PowerPoint presentation
- Prepare a joint brochure for patients
- Add a question about access to the FAQ section after the kidney failure question on NKDEP website
- Add Fistula First website to the related links page

The Forum is considering expanding its outreach dinners with surgeons to include PCPs. This could be an opportunity for NKDEP.

VII. Group Discussion

On early referral
Dr. Golconda raised the issue of referring to nephrologists early (i.e., CKD stage 2) to determine etiology. Dr. Narva feels that the critical question is whether the patient has access to someone who is competent to help him/her—this could be a nephrologist or a different practitioner.

On CVD
Dr. Eric Simon reminded the group about the recent recognition of CKD as an independent risk factor for cardiovascular disease (CVD), and asked about NKDEP's position on CVD. Cardiologists in addition to nephrologists want to advance this awareness. Dr. Simon said that this information may resonate more than progression. Dr. Narva said that the CVD message is starting to get out and that most interventions that slow CKD progression would also slow CVD. Dr. Simon said that he is promoting a non-silo approach, whereby intervening in one (e.g., CVD) helps with other (e.g., CKD).

Dr. Ed Roccella noted that NHLBI recognizes the link between CVD and CKD. Activities and planning are underway for working together and developing common messages. Dr. Narva suggested joint recommendations from the government education programs.

On reaching children
Dr. Kaskel commented on the need to extend NKDEP messages and materials to the pediatric population, especially because of the obesity epidemic in pediatrics. As kids transition to adulthood they need to carry the messages with them. Dr. Narva added that adult relatives need to carry the messages to kids, such as, "Your kidney disease is irreversible, but CKD in your kids can be prevented."

Ms. Singer added that the next NKDEP meeting could include information on NIDDK's childhood obesity programs.

VIII. Closing

Dr. Narva thanked everyone for attending the CP meeting.