

Kidney Interagency Coordinating Committee (KICC) Meeting - September 12, 2014

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

Meeting Participants and Summary

Andrew Narva, MD, FACP
Executive Secretary, KICC
Director, National Kidney Disease Education
Program
*National Institute of Diabetes and Digestive and
Kidney Diseases, NIH*
Phone: (301) 594-8864
Email: Andrew.Narva@nidDK.nih.gov

Patrick Archdeacon, MD
Senior Clinical Adviser, Office of Medical
Policy/CDER
Food and Drug Administration
Phone: (301) 796-3952
Email: Patrick.Archdeacon@fda.hhs.gov

Will Black
Assistant Director, Health Care
U.S. Government Accountability Office
Phone: (202) 512-6482
Email: BlackW@gao.gov

Susan Crowley, MD, FASN
National Program Director for Kidney Disease &
Dialysis
Veterans Health Administration
Phone: (203) 932-5711
Email: Susan.Crowley@va.gov

Paul Eggers, PhD
Program Director, Kidney and Urology
Epidemiology
*National Institute of Diabetes and Digestive and
Kidney Diseases, NIH*
Phone: (301) 594-8305
Email: EggersP@extra.nidDK.nih.gov

Sharrilyn Evered, PhD
Social Science Research Analyst, Population
and Community Health
Division of ESRD, Quality Improvement Group
Centers for Medicare & Medicaid Services
Phone: (410) 786-3079

Email: Sharrilyn.Evered@cms.hhs.gov
Michael Flessner, MD, PhD
Director of Inflammatory Renal Diseases,
Division of Kidney, Urologic, and Hematologic
Diseases
*National Institute of Diabetes and Digestive and
Kidney Diseases, NIH*
Phone: (301) 451-4901
Email: Mike.Flessner@nih.gov

Indira Jevaji, MD, MSL
Medical Officer/Advisor, Population and
Community Health
Division of ESRD, Quality Improvement Group
Centers for Medicare & Medicaid Services
Phone: (410) 786-1753
Email: Indira.Jevaji@cms.hhs.gov

Corissa Kiyan
Senior Analyst, Health Care
U.S. Government Accountability Office
Phone: (202) 512-5225
Email: KiyanC@gao.gov

Hannah Marston Minter
Senior Analyst, Health Care
U.S. Government Accountability Office
Phone: (202) 512-2646
Email: MarstonMinterH@gao.gov

David Miller, MD, MPH
Health Science Policy Analyst
*National Institute of Diabetes and Digestive and
Kidney Diseases, NIH*
Phone: (301) 496-6623
Email: Dm350g@nih.gov

Marva Moxey-Mims, MD

KUH Deputy Director for Clinical Research
Director, Pediatric Nephrology and Renal
Centers Programs
*National Institute of Diabetes and Digestive and
Kidney Diseases, NIH*
Phone: (301) 594-7717
Email: MoxeyMimsM@extra.niddk.nih.gov

Eileen Newman, MS, RD

Associate Director, National Kidney Disease
Education Program
*National Institute of Diabetes and Digestive and
Kidney Diseases, NIH*
Phone: (301) 435-8116
Email: Eileen.Newman@nih.gov

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
Phone: (202) 782-6462
Email: James.D.Oliver@us.army.mil

Lauren Oviatt

Health Insurance Specialist, Office of Clinical
Standards and Quality, Clinical Standards
Group
Centers for Medicare & Medicaid Services
Phone: (410) 786-4683
Email: Lauren.Oviatt@cms.hhs.gov

William Polglase

Kidney, Urology & Hematology Information
Office of Communications and Public Liaison
*National Institute of Diabetes and Digestive and
Kidney Diseases, NIH*
Phone: (301) 435-8115
Email: William.Polglase@nih.gov

Diane Reid, MD

Medical Officer, Vascular Biology and
Hypertension Branch
National Heart, Lung, and Blood Institute, NIH
Phone: (301) 402-3824
Email: Diane.Reid@nih.hhs.gov

Sharon Saydah, PhD

Commander, United States Public Health
Service Division of Diabetes Translation
Centers for Disease Control and Prevention
Phone: (301) 458-4183
Email: Zle0@cdc.gov

Robert Star, MD

Director, Kidney, Urologic, and Hematologic
Diseases
*National Institute of Diabetes and Digestive and
Kidney Diseases, NIH*
Phone: (301) 496-6325
Email: starr@mail.nih.gov

Desmond Williams, MD, PhD

Team Lead, CKD Initiative, Division of Diabetes
Translation
National Center for Chronic Disease Prevention
and Health Promotion
Centers for Disease Control and Prevention
Phone: (770) 488-1158
Email: Desmond.Williams@cdc.hhs.gov

Susan Ziemann, MD, PhD

Medical Officer, Geriatrics Branch
Division of Geriatrics and Clinical Gerontology
National Institute on Aging
Phone: (301) 496-6761
Email: Susan.Ziemann@nih.gov

Presenters & Observers

Kerri Cavanaugh, MD, MHS

Assistant Professor of Medicine, Department of
Medicine, Division of Nephrology and
Hypertension
Vanderbilt University School of Medicine
Phone: (615) 936-7306
Email: Kerri.Cavanaugh@vanderbilt.edu

Julie Wright-Nunes, MD, MPH

Assistant Professor, Department of Internal
Medicine, Division of Nephrology
University of Michigan Health System
Phone: (734) 764-5178
Email: juwright@med.umich.edu

Grant Olan

Policy and Government Affairs Associate
American Society of Nephrology
Phone: (202) 640-4657
Email: Golan@asn-online.org

I. Welcome and Introductions

Andrew Narva, MD, FACP

The goal of the committee is to encourage cooperation, communication, and collaboration across federal agencies involved in kidney research and other kidney-related activities. This KICC meeting focused on assessing awareness of chronic kidney disease (CKD) and how the terminology used to frame questions related to awareness can impact the assessments. Also presented were the Centers for Disease Control and Prevention's (CDC) CKD Surveillance System and a progress report on Healthy People 2020 objectives related to kidney disease.

Dr. Narva recognized Dr. Paul Eggers, Program Director, Kidney and Urology Epidemiology, National Institute of Diabetes and Digestive and Kidney Disease (NIDDK), for his contribution to the KICC and his leadership on kidney-related issues. Dr. Eggers will be retiring in 2015.

II. Assessing Awareness of CKD: Discussion of National Health and Nutrition Examination Survey (NHANES)

Chronic Kidney Disease Awareness: Definition, Assessment, and Prevalence

Sharon Saydah, PhD

Centers for Disease Control and Prevention

Awareness of CKD must be promoted at various levels—among the general public, at the individual level, and at the provider level. These efforts can help to:

- Allow for earlier diagnosis and treatment of CKD;
- Raise awareness of symptoms and risk factors of progression;
- Improve adherence to clinical recommendation and therapies; and
- Slow CKD progression and reduce complications, morbidity, and mortality.

Awareness efforts targeted to the general public, such as the National Kidney Disease Education Program (NKDEP), World Kidney Day, and National Kidney Month, seek to create a general knowledge base. At the individual and provider level it is much more specific. For individuals, awareness efforts are designed to educate people about kidney health and promote better management of kidney disease. For providers, these efforts are designed to help them recognize kidney disease in their patients and provide information, training, and tools to enhance the care provided to patients with CKD.

Awareness of CKD remains relatively low across the general public, people living with CKD, and providers when compared to other chronic conditions such as hypertension and diabetes. Awareness levels are much higher in people diagnosed with hypertension (80 percent awareness) and diabetes (over 90 percent awareness). They know they have the condition and will self-report their diagnosis.

It is important to note that many people with CKD do not know that they have it. This makes measuring awareness difficult. There are those that have CKD and have been told of their condition, those that tests have shown to have CKD but have not been told by their provider, and those that have been told of their condition but have not recognized the need to take steps to manage their CKD.

Only 7.7 percent of people with CKD are aware that they have impaired renal function (based on NHANES). This may be in part due to how the question is asked. For patients 20 years and older the NHANES asks,

“Have you ever been told by a doctor or health care professional that you have weak or failing kidneys? Do not include kidney stones, bladder infections, or incontinence.”

Awareness does increase in relation to severity of disease. For example, for those with an eGFR over 90, awareness is below five (5) percent. Awareness rates increase significantly the lower the eGFR (e.g., eGFR 44 and lower) although there are significant variations between patients with microalbuminuria and macroalbuminuria. Research has shown that awareness does not result in treatment in accordance to recommended guidelines. (Tout et al, Am J Nephrol, 2012;35:191-197).

Another awareness study took place in Jackson, Mississippi among a cohort of African American patients. Patients were asked, *“Have you ever been told by a doctor or health care professional that you have kidney disease?”* In this study, overall awareness was 3.16 percent. For those patients with diagnosed CKD, awareness was 15.8 percent. Awareness was low in Stage 1 (2.7 percent). It was much higher in Stages 4 and 5 (65.9 percent).

Another study explored health awareness in African Americans (30 years and older) in Atlanta, Baltimore, Cleveland, Jackson, New Orleans, St. Louis, and Memphis. In this population, people recognized that diabetes, hypertension, heart disease, cancer, and HIV are significant risks. Fewer than five (5) percent recognized kidney disease as a risk.

Low Patient CKD Awareness: Opportunities for Intervention

Julie Wright-Nunes, MD, MPH
University of Michigan Health System

Dr. Wright-Nunes explored CKD awareness at the patient, provider, and system levels.

In multiple studies, patients with CKD have reported various levels of awareness—ranging from 5-35 percent of those diagnosed with CKD being unaware of this diagnosis. It is difficult to compare the findings of these studies because there is no continuity across research questions. In addition, there is a great deal of variability in terms of responses depending on how the question is phrased.

Researchers have looked at factors associated with lower awareness of CKD. These include less education, race/ethnicity, older individuals, and limited health literacy. Health literacy—defined by the Institute of Medicine as the capacity of a person to obtain, process, and understand basic health information and services needed to make appropriate health decisions—is a critical component to any awareness effort. Lower health literacy is associated with less desirable outcomes for many conditions and also impacts health-related behaviors and knowledge. There are six studies that assess limited health literacy in patients with CKD. In these studies, 9 to 32 percent of participants were found to have limited health literacy and it varied depending on the populations studied. Some of the associations related to low health literacy included lower eGFR, lower dialysis adherence, higher resource utilization, and less likelihood of being referred for transplant.

Health numeracy also impacts awareness and health outcomes. For example, one study found that among patients with lower health numeracy there was a higher proportion that were not transplanted or even listed for transplantation.

Qualitative research (e.g., focus groups and interviews) has identified some common themes in terms of patient awareness. These include

- Information related to CKD is difficult to hear, understand, and accept; and
- More information is needed and should be provided earlier.

Specifically, the type of information patients need includes: preserving kidney function, signs and symptoms, medications and therapies, renal replacement options, psychosocial support, and financial planning. In one study of more than 200 high-risk individuals, lack of good patient/provider communication was mentioned in every focus group.

Another factor associated with the incidence of CKD in the United States is access to care. In one study blacks and whites at risk of CKD experienced differences in both the availability and quality of their health care. Blacks were more likely to lack both health insurance and a regular source of care. The findings suggest that access to health care may play a role in ethnic/racial disparities in CKD incidence among persons at high risk for CKD.

Recognition of CKD by health care providers has also been studied. In one study of 178 primary care providers and 126 nephrologists, only 59 percent of family practitioners and 78 percent of general internal medicine practitioners correctly identified Stage 3 and 4 CKD in a patient (97 percent of nephrologists made the correct identification). The providers also reported a lack of awareness of guidelines and available resources. Another study explored the quality of patient-physician discussions about CKD care. Over 230 patient encounters were audiotaped. All the patients had diabetes and hypertension and approximately 25 percent had CKD. CKD was discussed in 26 percent of the encounters, primarily in relation to laboratory results. But only with one patient (2%) did a provider take the time to confirm that the patient understood what was said. Less discussion of CKD was more likely in patients who were college educated, patients with more co-morbidities, and by physicians who had more practice experience.

Another studied conducted focus groups of nurse practitioners and primary care physicians and asked them to identify challenges to talking to patients about CKD. The challenges identified included

- Low patient awareness/patients do not recognize CKD as a problem;
- Primary care provider did not consider CKD to be a problem;
- Providers' own lack of knowledge and skills;
- Fear of emotionally overwhelming the patient;
- Time/resource/reimbursement constraint; and
- Lack of educational resources.

Dr. Wright-Nunes conducted a similar study among nephrology fellows. While they thought education is important, participants also reported that patients can be managed even if they do not know the specifics of the disease process. They also reported a wide variety of patient backgrounds, assessing the level of patient understanding, and scheduling/time management as challenges.

At the system level there are also factors that can contribute to better outcomes for CKD. In particular, promoting more interdisciplinary care (e.g., chronic care model). This model promotes changing the paradigm in terms of patient education, provider education, and resource allocation (including IT, pharmacy, nutrition, etc.).

Screening could serve as a useful tool for educating patients and the general public, especially since lack of awareness in patients was cited by providers as a barrier to discussing CKD with patients. However, screening of the general population may not be cost effective and it may be better to focus screening efforts on patients with co-morbidities. While there are resources available (e.g., printed materials and online tools), assessment of many of these interventions is lacking. The quality of some printed materials has been assessed by using an NKDEP modified resource. Safe Kidney Care is an online resource for both patients and providers. It has been evaluated for usability and the evaluation is ongoing.

An interactive worksheet to help nephrologists discuss CKD with patients has been developed and evaluated by Dr. Wright-Nunes and colleagues with input from researchers at Vanderbilt University School of Medicine. After using the tool, which takes one to two minutes to administer, patients had a higher awareness of the following factors than the control group:

- CKD diagnosis;
- Estimate of kidney function;
- Stage of CKD; and
- Understanding of GFR.

Assessment of Awareness: Discussion of Methods and Suggestions for Alternate Approaches

Kerri Cavanaugh, MD, MHS
Vanderbilt University School of Medicine

The kidney disease community has a branding problem that makes it difficult to raise awareness among providers, patients, and the general public. There is no consistency in the terms used and the use of different terminology is confusing. For example, the American Medical Association still uses the terms chronic kidney failure and renal disease while much of the kidney disease community, including NIDDK, uses the term CKD.

The purpose of CKD self-report studies is to determine the prevalence within a population, determine the awareness within a population, characterize the patient's kidney health status, and evaluate a patient's understanding of their own kidney health status. As stated above, how questions designed to assess awareness about CKD are phrased can greatly impact the responses provided by patients.

- The Behavioral Risk Factor Surveillance System (BRFSS), with over 409,000 respondents, is the world's largest, ongoing telephone health survey. It includes questions about kidney disease. Participants are asked, "*Has a doctor, nurse, or other health professional EVER told you that you have kidney disease (not including kidney stones, bladder infection, or incontinence)?*" Very few people report that they have been told they have kidney disease with the likelihood of the patient answering yes increasing with age. Even for the oldest respondents, those answering yes are less than seven (7) percent.
- NHANES asks, "*Have you ever been told you have weak or failing kidneys (excluding kidney stones, bladder infections, or incontinence)?*" Of people with an eGFR less than 60 (and approximately 30 percent with proteinuria as well), awareness in all respondents CKD Stages 3 and 4 ranged from 8.2 – 11.2 percent. As in the other studies, awareness increased as the eGFR measure dropped.
- The Jackson Heart Health Study, with over 3,400 African American respondents, asked, "*Have you ever been told by a doctor or health care professional you have kidney disease?*" Participants can also self-report being on dialysis. Overall awareness was 15.8 percent and ranged from 2.7 percent for those with CKD Stage 1 to 65.9 percent for those with CKD Stages 4 and 5.
- The CARTaGENE Study asked, "*Has a doctor ever told you that you had kidney disease, such as renal failure, renal infection, or kidney stones? What kind of kidney disease was it—renal failure, renal infection, kidney stones or other? Do you or did you have dialysis treatment? Have you had a kidney transplant?*" In this study awareness ranges from four (4) percent (eGFR 45-59), 22 percent (eGFR 30-44), 75 percent (eGFR 15-29), 100 percent (eGFR 15 and under).
- NKF KEEP, with over 7,800 respondents with diabetes, asked, "*Have you ever been told you have kidney disease?*" or "*Have you ever been told by a doctor or health care professional you have kidney disease (do not include kidney stones, bladder infections, or*

incontinence.?)” As the albumin creatinine ratio (ACR) increased so did awareness, with highest awareness being among people with CKD Stages 3 to 5 and ACR> 300 mg/g (17.1 percent awareness).

As the studies listed above indicate, awareness is for the most part very low. It is especially low among patients with early CKD. Comparing question performance across these studies the researchers concluded that

- Questions are rarely the same across research studies;
- Some studies do not address early kidney disease;
- Terms used in questions may influence the response and its accuracy; and
- Purpose of the question is important.

Interventions can have a significant impact on awareness. To evaluate the intervention using the interactive worksheet (mentioned above) a five question survey was used. The survey included the following questions:

- Do you have a problem with your kidneys?
- Do you have chronic kidney disease?
- Do you have decreased kidney function?
- What stage of CKD do you have?
- What is your percent of kidney function?

While only 19 percent of respondents answered all five questions correctly, the intervention was effective in raising awareness.

- After the intervention over 90 percent of patients with CKD answered yes to the question, *“Do you have a problem with your kidneys?”*
- Awareness of CKD stage in patients increased by approximately 30 percent.
- Patients were able to identify their percent of normal kidney function increased by approximately 20 percent.

Discussion

- Dr. Eggers asked whether people participating in NHANES are informed of their condition and told to seek follow up care. This is important since CKD is often asymptomatic. At the higher eGFR levels people may not be aware of their condition. Dr. Saydah stated that participants are referred to care based on their conditions. Dr. Williams stated that this is significant in terms of awareness but also may mean that we are not asking the right question. It is a composite measure that captures everything across the system.
- Dr. Star asked why the renal fellows thought patient education was not important. Dr. Wright-Nunes stated that the study did not look at specific details. Dr. Cavanaugh stated that culture among clinical providers is an issue as is prioritizing activities. Dr. Wright-Nunes stated that they did ask the fellows about “teach back” and there was resistance among many to this technique because it is very time consuming.
- Dr. Moxey-Mims stated that the NKF KEEP study does not fit with the other studies because it is focused on screening. People are going to the screenings because they want to find out if they have kidney disease so it is a realistic expectation for awareness to be low. Dr. Cavanaugh responded that there are some issues in comparing the rates for screening or diagnostic activities or general population screenings but there are still many unknowns in relation to what people know and why people are coming to the screenings—some may be coming for evaluation of their kidney health status. With NKF KEEP it is hard to tease out

who is truly unaware of their status, those who have been diagnosed but do not understand the condition, and those who are coming in for other screenings such as hypertension.

- Dr. Jevaji stated that Centers for Medicare & Medicaid Services (CMS) is facing similar issues in terms of awareness among patients, nephrologists, and primary care providers. This is important research that can be valuable at the state level and can be useful to professional organizations (e.g., licensure issues) to improve awareness. CMS uses the term End Stage Renal Disease (ESRD), which cannot be changed due to statutory requirements. In addition, there are terms that patients do not understand. For example, many people do not understand the term “incontinence” but do understand if they are asked, “*Do you wet your pants?*” Dr. Cavanaugh responded that patients do not seem to equate incontinence with CKD so the lack of understanding of the term probably does not result in misclassification. However, kidney stones are confusing for patients as many think it is a symptom of CKD. There is not a consensus in the nephrology community as to whether kidney stones as a specific condition meet the definition of CKD.
- Dr. Jevaji stated that CKD/chronic kidney failure is increasing in children but they are not represented in studies. This population should be included in future studies.
- Dr. Crowley stated that provider uncertainty might be reframed as reluctance to inform patients of their CKD diagnosis because it is likely that other chronic conditions will have a much greater impact on the patient health (i.e., the patient will die due to conditions other than CKD). It might be more appropriate to reframe the question to ask, “*Are you at risk of kidney failure?*” After all, this is where there is the greatest concern.
- Dr. Zieman stated that there are concerns for older people related to the natural aging of the kidneys. Also, many medications put them at risk of kidney disease. Providers need guidance on how to address this with their patients and there also must be strategies in place to inform older patients. These strategies must acknowledge the limitation that many older adults have in terms of online communication.
- Dr. Narva stated that there is a move to link patient materials to the Electronic Health Record (HER) so that they will be automatically available for a given condition.
- Dr. Cavanaugh stated that patients are less empowered to participate in self-directed learning. They see their providers as the most trusted source of information, and it is important to look for ways to enhance this interaction. Microeducation (very short) interventions could be effective. Dr. Wright-Nunes added that information on barriers to awareness is also available from qualitative studies. Dr. Narva added that physicians are often the least skilled at educating patients. There is a need to reach out to nurses, dietitians, and pharmacists, as well as other providers in the health care setting. Ms. Newman added that community health workers—or promotores de salud in the Hispanic community—are also effective educators both in and outside of health care settings.
- Dr. Flessner commented on the need to target interventions to specific audiences. In his experience, African Americans communicate better with African Americans and the same holds true for various racial/ethnic groups, such as Latinos. This presents challenges for providers. It is necessary to look at the cultural issues.
- Dr. Jevaji stated CMS has the ESRD Network Program, which is targeting end-stage patients. The ESRD Networks could conduct quality improvement projects focused on evidence-based interventions.
- Dr. Wright-Nunes stated that provider materials should be targeted to those whose roles involve a lot of communication (e.g., dietitians and pharmacists). Physicians are not trained to educate people in medical school and may not feel equipped to provide education at encounters. However, the majority of CKD patients are not seeing dietitians and pharmacists. Physicians need materials to help them become better educators in order to bridge this gap.
- Dr. Narva asked if it is possible to change the NHANES questions related to kidney disease and whether it would be helpful to form a work group that could suggest alternative questions. Dr. Williams stated that CDC’s National Center for Health Statistics has a

framework for the survey and other stakeholders (e.g., NIH) can make recommendations. The original question proposed for NHANES included the phrases kidney disease or kidney failure. Once questions are proposed they are subjected to cognitive testing and rewritten at a lower literacy level. If a new question is proposed it would be subjected to the same process. While the current question may not reflect the terminology preferred by other stakeholders in the kidney disease community, it does have similar outcomes in terms of measuring awareness as some of the other studies presented. In addition, the NHANES process is linked to Healthy People 2020. Changing the question would prevent tracking of the measure over time. Also, 20 years ago the diabetes measure performed poorly. Over time, awareness has increased. This will happen with CKD.

- Dr. Star stated that regardless of how the question is asked, the findings indicate that awareness is low. The problem is not the phrasing of the questions. More focus needs to be on provider attitudes and why patients are resistant to learning their status and obtaining more information.
- Dr. Cavanaugh stated that the term “weak and failing kidneys” will work in relation to eGFR but for proteinuria it may not work. Adding a question like “*Do you have chronic kidney disease?*” may help capture people who have proteinuria but not reduced GFR. Dr. Williams stated that it is very difficult to add questions to NHANES. If a question is added one must be removed. Dr. Moxey-Mims added that a question focused on proteinuria without depressed GFR would probably not provide additional information since the patient would probably still be unaware of their condition. Dr. Cavanaugh stated that it is necessary to decide how to describe the condition of proteinuria without depressed GFR so that there is a common term. Should it be called CKD or something else?
- Dr. Cavanaugh stated that NHANES data indicates that 26 million people have CKD and 10 million of these people have proteinuria without depressed GFR. Providing conflicting information can be counterproductive.
- Ms. Oviatt stated that education can still take place, even if there are not common terms.

III. Update on CDC CKD Surveillance System

Desmond Williams, MD

Centers for Disease Control and Prevention

The CKD Surveillance System documents the burden of CKD and its risk factors in the U.S. population over time and tracks the progress of efforts to prevent, detect, and manage CKD. It also provides the means for evaluating, monitoring, and implementing quality improvement efforts by both federal and nonfederal agencies.

An advisory committee made up of major stakeholders guided the design of the system. A steering committee with over 50 people, assisted in the development of the surveillance system. Partner organizations included: Arbor Research Collaborative for Health, CDC, NIDDK, University of Michigan, Kidney Epidemiology and Cost Center, and University of California, San Francisco.

The process for developing the system included the following steps:

- Identify existing national and regional data sources;
- Identification of topics and measures relevant to CKD surveillance;
- Prioritize topics and measures;
- Evaluate each data source/topic-measure-indicator combination;
- Plan for integration of all the data source/topic-measure-indicator combinations into a functional national surveillance system;
- Assess the feasibility of integration of all the data sources;
- Pilot testing; and

- Final report, recommendation, and dissemination.

Key characteristics that informed the development of the system include:

- Simplicity,
- Availability,
- Flexibility,
- Data quality,
- Acceptability,
- Sensitivity,
- Positive predictive value for capturing true cases,
- Representative,
- Timeliness, and
- Stability.

The system is organized by topics/domains, measures, and indicators. A domain is a broad area within the surveillance system (e.g., prevalence of disease, risk factors for disease). Within each domain are measures—a specific topic that is measured. Indicators are the actual data that provide information about the measures. In addition, the system captures the public health concerns that are addressed by the measures and indicators.

The website that houses the system also includes general information on CKD (e.g., fact sheets) and information on special populations. There is a rotating spotlight feature and information on upcoming awareness days. There is also information on Healthy People 2020 and the activities of other federal partners (e.g., NIDDK, VA).

Selected Topic Areas
• Burden of CKD
• Awareness of CKD
• Burden of Risk Factors for CKD
• Health Consequences in CKD Patients
• CKD Processes and Quality of Care
• Health System Capacity for CKD

Usage of the website has varied over time. For example, since in March 2014 there were approximately 1,500 visits, 2,000 visits in April, 2,300 visits in May, 1,800 visits in both June and July, and 2,300 visits in August. Most users are from the United States but there are users from other countries. The home page is the most popular page in terms of visits. Tracking of users does show that people are accessing data on a wide range of measures and indicators. Most users spend 10 – 30 minutes on the site.

CDC has used the surveillance system to develop the National Chronic Kidney Disease Fact Sheet. In addition, CDC has developed 17 published manuscripts and an additional seven have been accepted, are under review, or are in preparation. Thirty-five (35) abstracts and presentations have been accepted at national and international conferences and five abstracts have been submitted to American Society of Nephrology 2014.

The system will be updated (version 3.0) in October 2014. Planned enhancements include more information on the home page related to risk factors and populations, rotating banner with headlines, improved visual layout, and more consistent organization. Search functionality will be improved across the site. Detail pages will include streamlined “go” buttons, enhanced maps with mouse-overs and histograms, and easier download of charts.

Next steps for the system include:

- Healthy People 2020 indicators are being updated;

- Generate more regional granularity within the United States (at state/county level) (e.g., work with CMS data, BRFSS);
- Increase international collaboration (China, Ireland, S. Korea, Canada, etc.);
- Acute kidney injury surveillance both as a risk factor and progression factor;
- Continue exploration of remaining data sources while ensuring that current data sources continue to supply data;
- Explore measures not examined thus far and keep open to the development of new measures by tracking recent advances in CKD, including any changes in laboratory technology, pharmacology, clinical guidelines, or identified risk factors (e.g., acute kidney injury); and
- Proposed American Society of Nephrology Symposium dedicated to CKD Surveillance.

The Kidney Interagency Coordinating Committee (KICC) can assist CDC by continuing to support data sharing and access, providing comments and suggestions, and identifying opportunities for data sharing, analysis, and reports. KICC members are encouraged to join the advisory committee. Other federal partners are encouraged to link their websites to the system. In addition, the KICC can provide input on how to achieve synergy between the United States Renal Data System (USRDS) and CDC CKD Surveillance System.

CDC is also working to access other data sources such as CMS and the Department of Defense.

Discussion

- Dr. Narva asked how the data are updated. Dr. Williams said that it is a very labor intensive process. All data for each indicator are updated and historic data are saved.
- Dr. Crowley stated that the VA is working with the University of Michigan to create a CKD registry. This could be an opportunity for partnership. Dr. Williams stated that the University of Michigan is the contractor for USRDS and the CDC's surveillance system, which could facilitate collaboration.

Healthy People 2020 Progress Report: The Good, Bad, and Ugly

Paul Eggers, PhD

National Institute of Diabetes and Digestive and Kidney Disease

The Healthy People initiative provides science-based, ten-year national objectives for improving the health of all Americans. For three decades, Healthy People has established benchmarks and monitored progress over time in order to

- Encourage collaborations across communities and sectors,
- Empower individuals toward making informed health decisions, and
- Measure the impact of prevention activities.

Healthy People's measures of disparities and inequity include differences in health status based on

- Race/ethnicity,
- Gender,
- Physical and mental ability, and
- Geography.

For Healthy People 2020 there are nine objectives related to CKD and 15 objectives related to ESRD. In Healthy People 2000, there were no objectives related to kidney disease. The Healthy People 2020 objectives and the current status in relation to the established targets are listed below

CKD Related Objectives

- CKD-1 CKD among adults (status: baseline only)
- CKD-2 Kidney function knowledge (status: baseline only)
- CKD-3 Kidney evaluation after kidney injury (status: target met)
- CKD-4 Recommended medical evaluation
 - 4.1 Persons with CKD (status: target met)
 - 4.2 Persons with CKD and diabetes (status: target met)
- CKD-5 Recommended medical treatment for persons with diabetes and CKD (status: getting worse)
- CKD-6 Cardiovascular care in persons with CKD
 - 6.1 Elevated blood pressure (status: baseline only)
 - 6.2 Elevated lipid levels (status: baseline only)
- CKD-7 Deaths among persons with CKD (status: informational)

ESRD Objectives

- CKD-8 New cases of ESRD (status: improving)
- CKD-9 Kidney failure due to diabetes:
 - 9.1 Among U.S. population (status: improving)
 - 9.2 Among persons with diabetes (status: target met)
- CKD-10 Nephrologist care before the start of renal replacement therapy (status: target met)
- CKD-11 Vascular access for hemodialysis patients:
 - 11.1 Arteriovenous fistula as the primary mode (status: improving)
 - 11.2 Catheters as the only mode (status: improving)
 - 11.3 Arteriovenous fistula or maturing fistula (status: target met)
- CKD-12 Wait-listed and/or received donor kidney transplant among persons under 70 years (status: little or no change)
- CKD-13 Receipt of kidney transplant:
 - 13.1 Within 3 years of ESRD (status: getting worse)
 - 13.2 Preemptive transplant at the start of ESRD (status: informational)
- CKD-14 Deaths among persons with ESRD
 - 14.1 Total number of deaths in persons on dialysis (status: target met)
 - 14.2 Within first 3 months of initiation of renal replacement therapy in persons on dialysis (status: improving)
 - 14.3 Cardiovascular deaths in persons on dialysis (status: target met)
 - 14.4 Persons with a functioning kidney transplant (status: little or no change)
 - 14.5 Cardiovascular deaths in persons with a functioning kidney transplant (status: target met)

It is important to note that disparities related to care and treatment outcomes remain. For example, with Objective CKD 11.1 (Increase the proportion of adult hemodialysis patients who use an arteriovenous fistula as the primary mode of vascular access) the target of 50.6 percent has been met for white but not for black patients. The same is true for Objective CKD 11.3 (Increase the proportion of adult hemodialysis patients who use arteriovenous fistulas or have a maturing fistula as the primary mode of vascular access at the start of renal replacement therapy). However, there are measures where outcomes for black patients are better. With Objective CKD 14.1 (Reduce the total death rate for persons on dialysis), blacks are significantly lower than the target of 190.8 deaths per 1,000 patients while whites are still significantly higher than the target.

Significantly, Objective CKD 13.1 (Increase the proportion of patients receiving a kidney transplant within three years of ESRD) has been declining for both whites and blacks. While whites still exceed the target of 20 percent, blacks are significantly below the target (approximately 10 percent). The United States has one of the highest rates of transplantation in the world. However, the rate of

ESRD in the United States is significantly higher than in other countries so there remains a very large population in need of a transplant.

Dr. Eggers concluded by noting that that data indicate that people are being treated for CKD and ESRD. While there may be limited awareness on the part of patients and some providers, for the most part the medical community is addressing the needs of these patients.

Discussion

- Dr. Cavanaugh stated that most of the objectives relate to ESRD. Objectives should also focus on early-stage CKD. Dr. Eggers stated that there are some objectives related to early-stage CKD and they are showing that people are getting treatment at these stages.
- Dr. Williams stated that when people are aware of their condition they work to address it. This is similar to what happened with diabetes awareness.
- Dr. Archdeacon noted that in some of the objectives there were large increases around 2003 and 2004. Dr. Williams noted that treatment guidelines were released at this time.
- Dr. Williams stated that cardiovascular care for people with CKD is still a challenge and that better measures need to be developed. Dr. Narva added that integrating CKD care into the care of other chronic diseases is a challenge.
- Ms. Oviatt stated that increased health insurance coverage has resulted in more people seeking care for CKD. CMS only covers care for patients with ESRD. One area for more research is looking at how increased rates of insurance coverage can result in care that slows the progression of CKD.
- Dr. Williams stated that CDC has analyzed how changes in Medicare guidelines have impacted diabetes care. Once a standard is set by Medicare it seems to translate across all health insurance, elevating the level of care for all people with insurance. In the future, it will be necessary to assess the impact of the Affordable Care Act. Dr. Narva added that currently, many people with CKD are underinsured. The NKDEP IT work group is working to make EHRs searchable for urine albumin and eGFR. A performance measure by the National Quality Forum and CMS would move this process forward.
- Dr. Archdeacon stated that people with diabetes and ESRD seem to do better than those with ESRD alone. Is diagnosis and management better for people with diabetes? Dr. Williams stated that care of people with diabetes has improved significantly and complications related to other chronic conditions, including ESRD, have been reduced.

Federal Agency Updates

Government Accountability Office (GAO)

GAO is studying several issues related to kidney disease, including Medicare's payment policy related to home dialysis and incentives in this area. It is also looking at Medicare's kidney education benefit, which appears to be underutilized—only 2 percent of eligible patients used it in 2010 and 2011, according to the 2013 USRDS Annual Data Report.

- Dr. Javaji stated that providers need guidelines on who is eligible for home dialysis and which patients make the best candidates.
- Dr. Narva stated that it is supposed to be the patient that makes the decision. The question should be framed in this manner.

- Ms. Oviatt stated that self-management training has been very successful with diabetes. CMS gets money to do this training. The CKD education benefit is set up in a different way. It is reimbursement (i.e., billing code) as opposed to a grant program.
- Dr. Flessner stated that they used the education benefit extensively in his clinic in Mississippi and approximately 50 percent of patients opted for home dialysis.
- Dr. Javaji stated that many physicians are uncomfortable prescribing home dialysis. They need training. This type of training can be done in medical schools and by medical societies.
- Mr. Black stated that because the benefit is not being used does not indicate that education is not occurring.
- Dr. Cavanaugh stated that the billing code only applies to physicians and physician extenders. In most settings, a nurse or other providers are delivering the education—it will never show up in the coding. If physicians are providing education they will usually just bill for the clinic visit since this is easier administratively. Expanding the benefit to include nurses could help capture the education that is being conducted.
- Dr. Javaji stated billing for ESRD is complicated. At the physicians it is a monthly, capitated rate. At the provider/facility level it is a bundled payment.
- Dr. Williams suggested forming a working group to address this issue.