

The National Kidney Disease Education Program: Improving Understanding, Detection, and Management of CKD

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The National Kidney Disease Education Program (NKDEP), an initiative of the National Institute of Diabetes and Digestive and Kidney Diseases, works to reduce the morbidity and mortality caused by chronic kidney disease (CKD) and its complications. Established in 2000, the NKDEP initially focused on increasing awareness in at-risk populations and helping the laboratory community recalibrate serum creatinine measurement methods and begin using a revised equation to estimate glomerular filtration rate. Expanding its focus in recent years, the NKDEP now works to improve provider practices by collaborating with health systems, community health centers, and professional associations to encourage testing and treatment of patients. Among its top priorities is to develop such resources as clinical encounter tools, patient education aids, and training programs that help primary care professionals better identify and care for patients with CKD. Other priorities include improving the coordination of federal responses to CKD and addressing the standardization of measurement and reporting of urine albumin. Improving CKD detection and management is an important challenge. To succeed, the NKDEP must work in close partnership with the renal community, public health agencies, professional associations, and voluntary organizations that serve at-risk and patient communities.

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INDEX WORDS: Chronic kidney disease; estimated glomerular filtration rate; creatinine standardization; UACR; patient education; NKDEP; NIDDK; Chronic Care Model.

Chronic kidney disease (CKD) is a significant public health problem in the United States. Millions of Americans have diabetes or high blood pressure, the 2 leading risk factors for kidney failure.¹ An estimated 26 million Americans have CKD or albuminuria.² Recent data show that 485,015 people are on dialysis therapy or living with a kidney transplant.¹ Kidney failure cost the health care system approximately \$32.5 billion in 2004.³

Progression from CKD to kidney failure can be delayed if it is detected and treated early. Therapy with angiotensin-converting enzyme inhibitors or angiotensin receptor blockers decreases proteinuria and slows disease progression.^{4,5} Controlling blood pressure to less than 130/80 mm Hg has been shown to be beneficial,⁶ and there is evidence that intensive glycemic control slows progression from microalbuminuria.⁷

Improvement in both CKD screening and management is needed. A survey conducted between October 2006 and February 2007 found that only 38% of laboratories that report serum creatinine followed the recommendation to report estimated glomerular filtration rate (eGFR).⁸ Other investigators found that less than 40% of patients with an eGFR less than 30 mL/min/1.73 m² were coded with a CKD diagnosis.⁹ Despite strong evidence of benefit from multiple studies, the percentage of diabetic patients with CKD receiv-

ing angiotensin-converting enzyme inhibitors or angiotensin receptor blockers has been slow to increase.¹

A NATIONAL RESPONSE

The National Kidney Disease Education Program (NKDEP) was established in 2000 by the National Institute of Diabetes and Digestive and Kidney Diseases (NIDDK). The program's chief objective is to decrease the morbidity and mortality caused by CKD and its complications. Specifically, the NKDEP aims to improve the early detection of CKD, facilitate identification of patients at greatest risk of progression to kidney failure, and promote evidence-based interventions to slow the progression of CKD. The NKDEP is a parallel initiative to the National Diabetes Education Program, also located within the NIDDK.

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The NKDEP emphasizes the importance of screening to identify people with CKD as early as possible in the course of their disease. The program also promotes effective treatments and management strategies for patients with CKD and facilitates implementation of appropriate interventions. In pursuit of these goals, the NKDEP works in collaboration with a range of government, non-profit, and health care organizations to raise awareness in people at risk of kidney disease about the need for testing and the benefits of early detection, provide resources and tools to help health care providers better detect and treat kidney disease, and support changes in the laboratory community that yield more accurate, reliable, and accessible test results.

PROGRAM HISTORY

The NKDEP initially focused on at-risk patients, developing a variety of awareness-raising and educational materials (eg, website, brochure, print and radio public service announcements, and video). Formative research was conducted with at-risk populations, patients with CKD, and providers, and a Steering Committee was formed so the program could benefit from the advice of representatives from the renal community and target audiences. Materials were developed for distribution in dialysis clinics, encouraging dialysis patients to alert family members to their increased risk of CKD.

Beginning in April 2003, the NKDEP piloted an awareness campaign targeting at-risk patients—You Have the Power to Prevent Kidney Disease—in 4 cities: Atlanta, GA; Baltimore, MD; Cleveland, OH; and Jackson, MS. In each city, interested volunteers formed coalitions to plan and implement kidney disease awareness activities using NKDEP materials and resources. The campaign was launched nationally in June 2004 with media outreach and dissemination of campaign materials through more than 30 partner organizations.

A crucial early NKDEP effort was the formation of the Laboratory Working Group (LWG), which brought together some of the nation's leading clinical chemists and nephrologists to address issues related to laboratory measurement of kidney function using eGFR. The LWG began work on standardizing serum creatinine determinations to yield more accurate estimates of GFR.

This led to the publication in 2006 of comprehensive recommendations in *Clinical Chemistry*¹⁰ and the launch that year of the Creatinine Standardization Program (CSP), discussed in greater detail later. Two fact sheets, *Rationale for Use and Reporting of Estimated GFR* and *Suggestions for Laboratories*, were developed for the laboratory community by the LWG to promote routine reporting of eGFR and creatinine standardization, respectively.

Another early program was the African American Family Reunion Initiative. This program encourages families to use reunions and other gatherings as occasions to discuss the connection between diabetes, high blood pressure, and kidney disease and encourage those at risk to be tested for kidney disease. A *Family Reunion Health Guide* and companion website¹¹ were developed to provide family members with materials and ideas for incorporating this information into their events.

DEVELOPMENT OF NEW PROGRAMS

The NKDEP is guided by the Chronic Care Model,¹² which offers a strong framework for identifying system-level change concepts that can engage both providers and patients in improving CKD detection and management. The program relies on guidance from experts in the health care and public health communities, as well as primary and secondary research, to inform program and materials development. These and other experts contribute ideas and recommendations through participation in a Coordinating Panel, which meets annually, and through ongoing informal communications.

In addition to the Coordinating Panel and the LWG, the NKDEP has formed several ad hoc working groups over the years. A Quality Indicators Working Group explored the development of quality indicators for CKD in Medicare beneficiaries hospitalized for cardiovascular disease. A Dialysis Working Group advised the NKDEP on opportunities related to engaging dialysis patients in outreach to at-risk family members.

CURRENT ACTIVITIES

Laboratory Professional Outreach

In partnership with the American Association for Clinical Chemistry (AACC) and the Interna-

tional Federation for Clinical Chemistry and Laboratory Medicine, the NKDEP is working with laboratory professionals worldwide to improve the accuracy of serum creatinine measurements, which are critical to the diagnosis of CKD. Historically, creatinine determinations have not been standardized, resulting in significant differences in results reported to providers, depending on the laboratory and method used.

The NKDEP CSP aims to eliminate this interlaboratory variability and yield more accurate measurements of serum creatinine. This in turn will enable more accurate and reliable estimates of GFR. The CSP provides information to help manufacturers, clinical laboratories, and others in the laboratory community recalibrate their serum creatinine measurement methods. It also supports manufacturers' efforts to encourage their laboratory clients to use a revised GFR-estimating equation when they have recalibrated their methods. Since CSP launched in 2006, laboratory professionals and equipment manufacturers in the United States and Europe have become active participants in the effort. The LWG has sponsored symposia explaining the initiative at leading clinical chemistry conferences.

In late 2006 and early 2007, the NKDEP surveyed a representative sample of clinical laboratories conducting routine chemistry in the United States.⁸ The objective was to determine the prevalence of eGFR reporting with serum creatinine determinations and related practices. The key finding, as noted, was that only 38% of laboratories that report serum creatinine also report eGFR, as recommended by NKDEP, AACC, and National Kidney Foundation.

As part of its effort to promote routine reporting of eGFR, the NKDEP has partnered with the American Society of Nephrology and other key organizations, including the AACC, American Diabetes Association, and College of American Pathologists, to encourage eGFR reporting by all hospital and commercial clinical laboratories in the United States. A letter endorsed by all partnering organizations urging nephrologists to help facilitate reporting of eGFR was sent to the American Society of Nephrology membership in advance of World Kidney Day 2008.

Most recently, the LWG published protocols for the measurement of creatinine using whole-blood devices¹³ and began work on standardiz-

ing the measurement and reporting of urine albumin, a critical measure for the detection of CKD.

Health Care Provider Outreach

The NKDEP is working to improve provider practices by collaborating with health systems, community health centers, professional associations, and others to encourage routine testing and proper treatment of patients.

Among NKDEP top priorities is to develop resources and tools that can help health care providers, especially those in primary care settings, better identify and care for patients with CKD. Primary care providers may perceive that CKD is a specialist disease and that patients with CKD require treatment by a nephrologist or in a renal clinic. As such, they may miss opportunities for the early diagnosis and proper treatment that can help keep kidneys healthier longer.

The NKDEP recently developed 2 tools to educate providers and patients about appropriate testing. For health care professionals, it created a clinical reference sheet that clearly explains the 2 key tests (urine albumin-creatinine ratio [UACR] and eGFR) used to diagnose kidney disease.¹⁴ Another tool, currently available in English, Spanish, Chinese, and Vietnamese, is a patient-education pad about eGFR for use in clinical interactions. Tear-off sheets explain GFR in very simple language, provide space to record a patient's results, and outline simple steps patients can take to keep their kidneys healthy. The back of the pad features concepts and talking points to help providers educate their patients.

These and other materials are being disseminated through a series of strategic partnerships. The *Quick Reference on UACR and GFR* was sent to approximately 11,000 diabetes educators through a joint mailing with the American Association of Diabetes Educators as part of National Kidney Month in March. The NKDEP worked with the Arkansas Wellness Coalition, whose members include the American Heart Association, Arkansas Blue Cross and Blue Shield, and state chronic disease programs, to send the reference sheet and a promotional piece for the GFR pad to health care providers. The NKDEP is working with the Blue Cross and Blue Shield of Oklahoma and Aetna to send materials to both providers and patients.

The NKDEP considers community health centers (CHCs) to be crucial partners in its efforts. Health centers serve many of the people at greatest risk of CKD: those who have diabetes or hypertension or are African American or Hispanic. In addition, CHCs have shown the capacity to systematically improve outcomes through the Health Disparities Collaboratives initiative of the Health Resources and Services Administration.¹⁵ Of particular interest to the NKDEP are CHCs that participate in Diabetes Collaboratives. Many therapeutic interventions for CKD are similar to those required for optimal diabetes care (eg, control of blood pressure, lipid levels, and glucose levels). The most important additional interventions are screening for comorbid conditions (eg, anemia, malnutrition, and disorders of mineral metabolism), dietary modification, educating patients about the progressive nature of CKD, and planning for renal replacement therapy.

In February 2008, the NKDEP launched the CHC-CKD Pilot with a group of 5 health centers in the Northeast United States and in cooperation with Fair Haven Community Health Center, the Community Health Center Association of Connecticut, and the New England Clinicians Forum. Although the pilot is still in its formative stages, the NKDEP believes it can help health centers improve CKD detection and management by offering assistance in 2 key areas.

The first of these is provider education. There are numerous educational materials for health professionals related to CKD. However, some are expensive, some are very complex, and few are tailored to the needs of CHCs. With input from health centers, NKDEP hopes to develop training materials and/or programs. These could be as substantive as full-day training sessions or as simple as clinical reference cards.

The second is clinical encounter tools. The NKDEP is interested in working with health centers to develop new clinical tools to support better CKD detection and management; eg, electronic health record prompts, diabetes care protocols that increase emphasis on kidney complications, and clinical algorithms.

Patient and Public Outreach

The NKDEP recently completed promoting the third year of its Family Reunion Initiative, as dis-

cussed. Since the initiative began, the NKDEP has distributed 27,000 hard copies of the *Family Reunion Health Guide* and an additional 25,000 copies have been downloaded from the NKDEP website. In an effort to tailor materials and messages to specific at-risk populations, the NKDEP developed a *Make the Kidney Connection* brochure for people with diabetes and high blood pressure,¹⁶ a brochure entitled *Kidney Disease: What African Americans Need to Know*,¹⁷ and *Aprenda a Proteger Sus Riñones*, a brochure for Spanish speakers.¹⁸

Federal Partner Outreach

To help improve the coordination of federal responses to CKD across many federal agencies, the NKDEP has taken an active role in coordinating the NIDDK Kidney Interagency Coordinating Committee (KICC). In doing so, NKDEP has expanded the KICC from an annual meeting of agency representatives to a year-round initiative that assists members in sharing information about their CKD activities and opportunities to collaborate. The NKDEP supports communication among KICC members through a quarterly newsletter, *KICC News*, which highlights new and important CKD-related activities within the federal government. In addition, the NKDEP coordinates annual KICC meetings about CKD, the first of which took place in June 2007. Last, the NKDEP is developing an online directory that will summarize and provide contact information for the various CKD-related activities taking place across federal agencies.

FUTURE PRIORITIES

In the future, the NKDEP will continue to provide greater focus on the clinical setting while placing a high priority on developing new partnerships that can help extend the program's resources and reach.

First, the program hopes to expand its work with CHCs. In tandem with the development of materials, training programs, and other resources as part of the newly launched CHC-CKD pilot, the NKDEP plans to explore similar pilots in other regions of the country. The goal is to build an informal practice-based research network that enables more rapid identification and dissemination of best practices for improving CKD detec-

tion and treatment. In addition to working directly with health centers, the NKDEP hopes to engage them through state primary care associations, existing practice-based research networks, and the National Association of Community Health Centers.

Second, the NKDEP plans to place a greater emphasis on patient education. Through several of the projects outlined, the program is testing short-form patient education materials that seek to help time-starved primary care providers quickly communicate essential information. As part of this effort, the NKDEP is exploring the development of brief web videos that model topic by topic how to explain key CKD concepts. A point of emphasis throughout will be the importance of patient self-management; what indicators (eg, eGFR, UACR, and blood pressure) patients should know and other steps they can take so they can have an active and informed role in their care.

Third, the NKDEP is working to engage more members of the health care team. In addition to the new materials for diabetes educators mentioned, the program has begun to work with State Diabetes Prevention and Control Programs to disseminate existing materials. Building on recent outreach to renal nutritionists, conducted in partnership with the Renal Dietitians Practice Group of the American Dietetic Association, the NKDEP plans to educate the broader nutritionist community about CKD.

Serving as both a channel for these projects and a distinct educational tool in itself, the NKDEP website (www.nkdep.nih.gov) is being thoroughly revised. The new site, to be launched in 2009, contains extensive new content for health care providers, laboratory professionals, patients, the public, and NKDEP partners. A new information architecture and interface will make it easier for users to find the information they need.

Improving CKD detection and management is as complex a challenge as it is important. To succeed, NKDEP must work in close partnership with nephrologists and others in the renal community, public health agencies, professional associations, and the wide variety of voluntary organizations that serve at-risk and patient communities. The program welcomes inquiries from these and other potential partners.

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