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## Toward a More Collaborative Federal Response to Chronic Kidney Disease

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Over the past twenty years, chronic kidney disease (CKD) has become recognized as a significant public health problem in the United States. It is a common and costly disease: it is estimated that CKD may affect 23.2 million Americans older than 20 years; (1) in 2006, costs for Medicare patients with kidney disease exceeded \$49 billion, or nearly one-quarter of all Medicare spending. (2)

CKD is generally easy to diagnose, and effective treatments exist. (3–5) National objectives reflecting quality of CKD care were included for the first time in *Healthy People 2010*. (6) Despite this recognition, the publication of a number of clinical guidelines, and significant effort on the part of voluntary health organizations and professional groups, data from the United States Renal Data System (USRDS) and other sources suggest that much work remains to be done to achieve acceptable levels of recommended care. In 2006, fewer than 35 percent of people with diabetes and kidney disease received basic care (i.e., an eye exam, lipid evaluation, and 2 measurements of hemoglobin A1c). (7) Seventy-three percent were treated with renin-angiotensin system antagonists, a level little improved over the previous 5 years. (8) Blood pressure control for CKD patients is poor; nearly half of the hypertensive patients in the National Health and Nutrition Examination Survey (NHANES) had uncontrolled blood pressure, and another quarter were unaware of their condition or left it untreated. (9) Fewer than 40 percent of patients with an estimated glomerular filtration rate (eGFR) less than 30 mL/min/1.73<sup>2</sup> were coded with a CKD diagnosis. (10) One third of patients do not see a nephrologist prior to initiation of renal replacement therapy and only 13 percent have seen a dietitian prior to initiation. (11) Approximately half of patients with no pre-dialysis nephrology care had pre-initiation hemoglobin levels less than 10 g/dL, compared with 35 percent of patients with greater than 1 year of nephrologic care. (12) For more than 80 percent of patients initiating hemodialysis, vascular access was provided by a catheter. (13)

As guardian of the nation's health, the Federal government has developed the infrastructure to promote population-based interventions which have proven effective in reducing the burden of other chronic illnesses, such as stroke and cancer. In addition, the Federal government has a unique role in addressing the morbidity associated with CKD through funding care for people with end-stage renal disease (ESRD). An effective, coordinated response by Federal health

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agencies to the public health challenge of chronic kidney disease could have a significant effect on the morbidity, mortality, and cost associated with CKD.

Current Federal efforts span a range of missions, including surveillance; professional and patient education; outreach to high-risk populations; quality improvement; and delivery of, as well as payment for, CKD treatment. Such activities are conducted by programs across several Federal health agencies. Considered as a whole, the Federal government appears to have a fairly comprehensive approach to CKD management.

However, Federal agencies do not function as a comprehensive system or, indeed, as a system at all. Many programs operate independently of each other, which increases the risk of contradictions, redundancies, and gaps. Even though agencies are doing excellent and needed work on CKD issues—indeed, this paper highlights several notable examples—the collective reach and impact of these programs fall short of their true potential. Improving communication and coordination among Federal CKD programs would therefore be a key step in improving the overall Federal response to CKD.

The barriers to achieving greater effectiveness begin with poor visibility. Federal program managers experience difficulty in learning about, or staying abreast of, what other Federal agencies do related to CKD.

Lack of coordination is among the sequelae of poor visibility: if program managers are unaware of what is happening, it becomes difficult for them to work together. If duplicated efforts are not visible, they cannot be avoided; if opportunities for collaboration are not identified, they cannot be capitalized upon; if populations of focus are not clearly defined, communities in need can fall through the cracks. What might otherwise be a well-coordinated group of Federal programs, with aligned objectives and clear divisions of labor, has historically been a band marching to the beats of different drummers.

In recent years, however, initiatives undertaken by 3 Federal agencies have made important advances in coordinating efforts. The Centers for Disease Control and Prevention (CDC) has begun to develop a surveillance system and public health analyses that require dialogue and coordination among numerous agencies. The Centers for Medicare and Medicare Services (CMS) has, through the successful Fistula First initiative and inclusion of chronic kidney disease in the scope of work of Quality Improvement Organizations, helped build relationships and infrastructure that support earlier diagnosis and treatment of CKD. The National Institute of Diabetes and Digestive and Kidney Diseases, through its National Kidney Disease Education Program, has reinvigorated and expanded the Kidney Interagency Coordinating Committee in ways that make it a robust vehicle to share information about activities, identify and disseminate promising practices and tools, and foster cross-agency collaboration.

## Centers for Disease Control and Prevention

In 2006, Congress appropriated funds to develop capacity and infrastructure at CDC for a kidney disease surveillance, epidemiology, and health outcomes program. These funds seeded what has now become the CDC CKD initiative. The CKD initiative is designed to develop and implement public health strategies for promoting kidney health. These strategies seek to prevent and reduce the progression of CKD, raise awareness about CKD and its risk factors, promote early diagnosis, and improve outcomes and quality of life for those living with CKD. CDC has developed collaborative relationships with research institutions, other Federal agencies, and national organizations that are currently engaged in CKD action. CDC's activities are designed to provide fundamental and timely public health information for the CKD professional and public audience.

CDC—in collaboration with the University of Michigan, University of California at San Francisco, and Johns Hopkins University—is attempting to establish a national surveillance system for CKD in the United States. (14) The surveillance system currently uses existing local and national sources of CKD data to quantify the CKD burden, identify gaps and deficiencies in existing data sources, and propose creative solutions and remedies to fill gaps and deficiencies. The surveillance project also is developing a plan to integrate all data sources into a functional surveillance system. This surveillance system will be made available through an interactive web-based interface that would provide current and trend data on the state of CKD.

CDC is collaborating with other Federal agencies, academia, national organizations, and the public to develop a CKD fact sheet that will provide definitive information on the burden and consequences of CKD in the United States that can be used by all partners. In collaboration with the National Institute of Health's (NIH) National Institute of Diabetes and Digestive and Kidney Diseases (NIDDK) and CDC's National Center for Health Statistics (NCHS), the CKD initiative supports the development, refinement, and collection of kidney measures in the NHANES survey of American adults and children. (15)

CKD Health Evaluation Risk Information Sharing (CHERISH), a collaborative project of CDC and the National Kidney Foundation, is a free health screening to identify individuals who have CKD or are at increased risk for developing CKD. Screening participants can learn if they have kidney disease or are at risk for kidney disease; they receive referrals if their results are outside of normal ranges, as well as a follow-up survey to assess their care after the screening.

CHERISH has developed an algorithm using data from NHANES that maximizes the yield of CKD detection and screening programs. CHERISH will assess the burden of kidney disease in a high-risk targeted population, determine the individual's subsequent access to care, and address the likelihood of disease progression in those with evidence of CKD. This study is currently being conducted in 8 sites in 4 states to test the feasibility of implementing such a program. Preliminary data suggest strong participation rates from the public; preliminary results were presented at October 2009 American Society of Nephrology meeting in San Diego. (16)(17)

CDC also collaborates with the Department of Veterans Affairs (VA) - Puget Sound Health Care System to examine the natural history of CKD and evaluate the rate of progression through the stages of CKD and development of complications using national VA data sources. (18)

The CKD Cost-Effectiveness Study, conducted by CDC in collaboration with the Research Triangle Institute, has developed and validated a lifetime simulation model to predict the development and progression of CKD in the United States (19). The program is now using the model to assess the cost-effectiveness of various public health interventions to prevent, delay, and manage CKD and its complications. The first application of the model was to test the cost-effectiveness of screening and early treatment of CKD. (20) CDC is also researching the direct and indirect economic cost of CKD through its Cost of Illness Study. (21)

CDC continues to work in close collaboration with other Federal agencies. CDC activities support CMS in its activities related to the Medicare Improvements for Patients and Providers Act of 2008 (see below), and CDC is collaborating with NIDDK to lead the development of new kidney objectives for *Healthy People 2020*.

## Centers for Medicare and Medicaid Services

In 2004, each person with CKD annually cost Medicare \$20,668, a 5.3 percent increase over the previous year, and 41 percent more than in 1993. Medicare expenditures for ESRD in 2006 were an additional \$22.7 billion; (22) they are projected to more than double, to \$55.6 billion,

by 2020. (23) Because the average cost of providing care for a dialysis patient is \$72,000 per year, (24) there are significant potential cost savings associated with implementation of interventions that help slow the progression of CKD. According to the USRDS, Medicare saves \$250,000 for each patient who does not progress to dialysis (based on \$65,000 annual cost of Medicare ESRD services and a 4-year life expectancy). (24) Patients with CKD, diabetes, and hypertension, either alone or in combination, represent the greatest disease burden to the Medicare program. In 2007, patients with CKD made up 9.8 percent of the general Medicare population, but expenditures associated with CKD amounted to 27.6 percent of costs. (25) There is a clear need for medical interventions that help slow the progression of CKD and reduce costs.

### Quality Improvement Organizations

Created by Congress in 1982, Quality Improvement Organizations (QIOs) work to improve the quality of services provided to Medicare beneficiaries. CMS interprets this to include a broad range of proactive initiatives that promote quality care. Included in its Scope of Work for the program are tasks that direct QIOs to provide technical assistance, including information exchanges, to Medicare providers to help them improve the quality of care they provide. (26)

The ninth Scope of Work, currently in effect, tasks QIOs with improving detection and care of CKD with the aim of decreasing progression of chronic kidney disease among Medicare beneficiaries. Specifically, CMS asks QIOs to focus on 3 areas: annual testing to determine the rate of kidney failure due to diabetes; use of ACE inhibitors and/or angiotensin receptor blockers to slow progression of CKD in patients with diabetes and hypertension; and timely placement of an arteriovenous fistula. (27)

Though these are important objectives in themselves, the strategies that QIOs employ to achieve them help advance a more comprehensive and coordinated approach to CKD management. CMS directs QIOs to increase provider use of tested and proven clinical practices; disseminate to providers and patients tools and resources that are already available through other Federal partners; and work in collaboration with others to achieve lasting system level changes across a variety of care settings (e.g., hospitals, nursing homes, and community health centers). (28)

### Fistula First Breakthrough Initiative

The CMS-led Fistula First Breakthrough Initiative (FFBI) has achieved remarkable success over the past 6 years—the percentage of prevalent hemodialysis patients in the United States with an arteriovenous fistula as their primary vascular access rose from 32.4 percent at the beginning of 2003 to 53.3 percent by August 2009. (29) The marked increase in fistula placement may be an indicator of more comprehensive and better coordinated management of CKD; additional progress will be difficult without improvements in early detection, patient education, and early referral.

Further collaboration will be required to achieve the new CMS goal of a prevalent arteriovenous fistula utilization rate of 66 percent. With leadership from CMS—and support from the ESRD Networks, QIOs, and the more than 60 diverse groups in the FFBI Coalition—the FFBI works to implement 7 strategies to achieve this new goal. (30) As with QIOs, these strategies demonstrate how CMS can promote a more comprehensive response to CKD. The FFBI Strategic Plan requires a high degree of partnership and coordination across specialties, practice settings, and professional communities. Early referral to nephrologists is a key objective; late referral has been shown to be a major determinant in the use of central venous catheters at hemodialysis initiation. (31) The Strategic Plan seeks to engage a diverse group of referring physicians and associated healthcare systems to increase awareness of the importance of AV

fistulas, and especially the need for early referral to allow for placement and maturation prior to initiation of hemodialysis.

The ESRD Networks and QIOs play a crucial role in this effort, disseminating information and providing technical assistance to the numerous providers and partners with whom they are already working. These partners are indeed a key component of the FFBI's success. By sharing information with and among a wide variety of stakeholders (e.g., renal and other professional associations, dialysis providers, vascular access surgeons, hospital and primary care associations, insurance providers, and community groups) the FFBI Coalition has helped reach CKD patients and those in a position to influence practice patterns. The 6 CKD educational sessions covered under the Medicare Improvements for Patients and Providers Act of 2008 provide a new opportunity to educate patients and caregivers on the importance of timely placement of vascular access.

**National Institutes of Health**—The NIDDK and other institutes at NIH support a \$523 million portfolio of kidney research. (32) The scope of this research is broad, examining basic, clinical, and epidemiologic aspects of kidney disease. The USRDS, the annual NIDDK-funded analysis of data on kidney disease in the United States, is used in quantifying public health trends, guiding funding priorities, and designing targeted kidney research programs. Of particular interest to other Federal agencies is the Chronic Renal Insufficiency Cohort Study, a longitudinal cohort study of 4,000 people with CKD, half of whom have diabetes. (33) Longitudinal data is just becoming available, but the study will likely play a large role in informing efforts to predict risk for progression of CKD and guide population management interventions. The National Kidney Disease Education Program (NKDEP) was established by NIDDK in 2000 to reduce the morbidity and mortality caused by CKD and its complications. NKDEP aims to improve early detection of CKD, facilitate identification of patients at greatest risk for progression to kidney failure, promote evidence-based interventions to slow progression of CKD, and support the coordination of Federal responses to CKD. To achieve its goals, NKDEP works in collaboration with a range of government, nonprofit, and health care organizations to: raise awareness among people at risk for CKD about the need for testing; provide information, training, and tools to help health care providers better detect and treat CKD; and support changes in the laboratory community (e.g., standardizing the measurement and reporting of serum creatinine and eGFR) that yield more accurate, reliable, and accessible test results. Central to NKDEP's approach is the concept that CKD should be identified and addressed in the primary care setting, and that managing CKD prior to referral can improve patient outcomes.

As a Federal program devoted to improving health outcomes associated with chronic kidney disease, NKDEP is well suited to serve as a catalyst for a coordinated Federal response to CKD. An appropriate vehicle has existed since 1987: the Kidney Interagency Coordinating Committee, based at NIDDK and mandated by Congress to encourage cooperation, communication, and collaboration among all Federal agencies involved in kidney research and other activities.

Beginning in 2007, NKDEP took an active role in coordinating the Kidney Interagency Coordinating Committee, expanding it from a brief *pro forma* annual meeting into an active, multifaceted, year-round initiative. The committee has been revitalized by its member agencies and now serves as a forum to raise awareness of the range of activities within the Federal government around CKD detection and treatment. Improved interagency communication, facilitated in part by a newsletter and Web-based tool (see below), has produced gratifying efforts at collaboration, particularly among the NIH, CDC, and CMS.

One novel product of the Kidney Interagency Coordinating Committee has been a matrix to document the range of programs undertaken by each agency. The KICC Matrix, shown in its concise reference form in Figure 1, is available on the NKDEP website as an interactive matrix that enables Federal agencies and others to easily summarize all CKD-related activities across 9 Federal agencies. (34) Visitors can: click on a response category (e.g., Quality Improvement/Evidence of Therapy, Scientific Research, Professional Education and Outreach) to learn about agency activities in that area; click on an agency name to learn about its activities across response categories; or click a Summary button to quickly learn what a particular agency is doing in a particular response category. Contact information for each agency and initiative is also provided to foster additional collaboration.

**Other Efforts**—In addition to the CDC, CMS, and NIH efforts described above, the Indian Health Service, Department of Veterans Affairs, and Department of Defense all support direct care systems which serve populations with a high prevalence of, or at high risk for, CKD. Despite limited resources, each of these systems has demonstrated the ability to implement systematic change to improve care in CKD, diabetes, and other chronic illnesses. As Federally funded direct-care systems, they are accountable to the public and have a strong incentive to deliver care in the most cost-effective manner. The systems can be surprisingly innovative and effective: the VA electronic health record is highly regarded, and American Indians with diabetes appear to have reduced rates of ESRD despite growing prevalence of diabetes.

## Recommendations for Further Collaboration

In addition to the improvements in communication and cooperation made possible by the Kidney Interagency Coordinating Committee—as well as other opportunities for coordinated planning, such as *Healthy People 2020*—there are several priority areas in which Federal agencies can better align their efforts and amplify their collective impact. These include: a cross-agency initiative to define quality improvement measures relevant to CKD; a systematic assessment of existing clinical guidelines related to CKD, out of which may emerge a collective effort to identify and close gaps in knowledge about primary and secondary CKD education; joint development and distribution of prediction tools for progression to kidney failure; and coordinated efforts to strengthen educational offerings and materials for primary care providers.

It also will be important to look beyond those Federal agencies working directly on CKD toward new models of collaboration and collective planning being adopted by others within the Federal government. One example is the Clinical Decision Support (CDS) Collaboratory—a joint initiative of the Office of the National Coordinator for Health IT, Agency for Healthcare Research and Quality, and the HHS Personalized Healthcare Initiative—which brings together Federal agencies to share CDS-related information and support. Such a forum provides a vehicle for Federal agencies to work together to improve clinical decision support on CKD-related issues

## Conclusion

The health agencies of the Federal government devote great resources to reducing the burden of chronic kidney disease. Although these efforts, from surveillance of early CKD through quality improvement of ESRD care, are comprehensive in scope, they are not perceived as such. This may be due to the failure of the various agencies to coordinate their efforts. With appropriate coordination, the effectiveness and coherence of each agency's efforts could be enhanced and implementation of system changes needed to improve CKD outcomes could be promoted. Collaboration among Federal healthcare agencies is likely to enhance efforts to reduce the burden of CKD in the United States.

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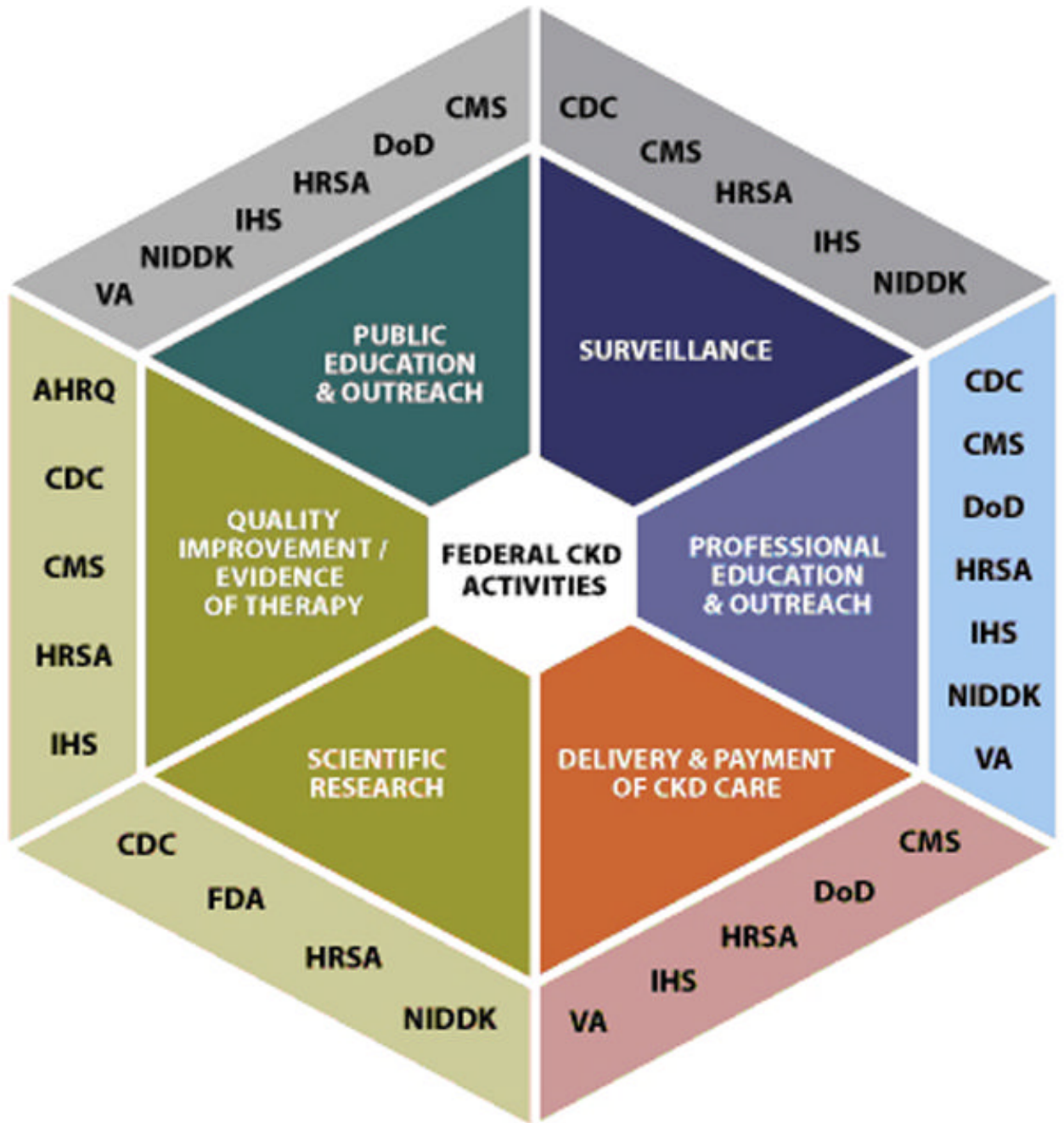


Figure 1.