

# Establishing a National Chronic Kidney Disease Surveillance System for the United States

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Despite the recognized importance of chronic kidney disease (CKD), the United States currently lacks a comprehensive, systematic surveillance program that captures and tracks all aspects of CKD in the population. As part of its CKD Initiative, the Centers for Disease Control and Prevention (CDC) funded two teams to jointly initiate the development of a CKD surveillance system. Here, we describe the process and methods used to establish this national CDC CKD Surveillance System. The major CKD components covered include burden (incidence and prevalence), risk factors, awareness, health consequences, processes and quality of care, and health system capacity issues. Goals include regular reporting of the data collected, plus development of a dynamic project web site and periodic issuance of a CKD fact sheet. We anticipate that this system will provide an important foundation for widespread efforts toward primary prevention, earlier detection, and implementation of optimal disease management strategies, with resultant increased awareness of CKD, decreased rates of CKD progression, lowered mortality, and reduced resource utilization. Final success will be measured by usage, impact, and endorsement.

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Chronic kidney disease (CKD) has been recognized as a public health priority since the late 1980s (1,2). A dedicated, comprehensive, and systematic surveillance program that captures and tracks all aspects of CKD in those not yet receiving renal replacement therapy is fundamentally important for the ongoing assessment of the national CKD burden. Dissemination of its findings would raise awareness about this disease and its impact on the population and health care system, and would provide the impetus for public health action.

According to the most recent estimates from the National Health and Nutrition Examination Survey (NHANES), 13% of the US adult population has CKD (3). Kidney disease is listed as the ninth most common cause of death by the National Center for Health Statistics (4). However, most patients are unaware of their declining kidney function until it is in its late stages (5,6), or they succumb prematurely, typically to cardiovascular disease (7,8). Progression of CKD, and its attendant comorbidity, can be slowed or potentially even halted with optimal medical

care (9–11), with implications for increased lifespan, quality of life, and lower societal cost. Therefore, it is critical to identify those at risk or in the early stages of the disease, with the intent of effective implementation of proven preventive and therapeutic strategies.

Following a legislative mandate from the US Congress (12), the Division of Diabetes and Translation at the Centers for Disease Control and Prevention (CDC) funded two teams at the University of Michigan and Johns Hopkins University to jointly initiate the development of a CKD surveillance system in the United States.

This article describes the process and methods used toward establishing a national CDC CKD Surveillance System, followed by a discussion about key aspects, including successes and challenges faced during the early phases of its development.

## Foundational Work

### *Definition of Surveillance and Attributes of an Ideal Surveillance System*

Disease surveillance has been defined by the CDC as “ongoing, systematic, collection, analysis and interpretation of health data essential to the planning, implementation and evaluation of public health practice, closely integrated with the timely dissemination of these data to those who need to know” (13).

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Surveillance can be “active” or “passive.” Active surveillance typically involves interaction with providers to identify cases of disease, often by visiting health care facilities and reviewing medical records, as well as interviewing health professionals, patients, and/or persons in the community. Passive surveillance typically involves using existent data, which can be mandated for collection or assembled for other reasons (14). Although active surveillance is typically more accurate and less bias-prone, it typically requires more resources and can involve privacy and confidentiality issues. Thus, most chronic disease surveillance systems, particularly on a national level, use a passive approach.

The attributes of an ideal chronic disease surveillance system, in general, have been characterized as (15): (1) *simplicity* of system structure and operation; (2) *flexibility* to look at new questions posed by researchers and to adapt to changes in technology and reporting definitions; (3) high *data quality*; (4) *acceptability*, or enthusiasm and willingness on the part of stakeholders and data sources to participate in the system; (5) a high degree of *sensitivity* for capturing all events and monitoring trends; (6) a high *positive predictive value* for capturing true cases; (7) *representativeness* of information pertaining to the general US population; (8) *timeliness* in the processing and delivery of information necessary to implement health care changes; and (9) *stability* of the system to reliably operate and provide information when users call upon it.

### Specific Aims

Two multidisciplinary teams based at the University of Michigan and Johns Hopkins University were selected to collaboratively design and implement a national CKD surveillance system with the CDC. Teams consisted of epidemiologists, generalist and specialist clinicians, biostatisticians and others. The specific aims for the development of the CDC CKD Surveillance System project, as conceived by the CDC and the teams, appear in Table 1.

### Establishment of a Structure and Process

To facilitate collaboration within the project, a steering committee, including all academic and CDC members and guided by the teams’ Principal Investigators and the CDC Technical Advisor, was formed. It was envisaged that members would meet monthly to share information, discuss options, gather input, and make decisions. In addition, both Principal Investigators and their respective team members would meet on a weekly basis by teleconference. After the steering committee’s establishment, the two teams drafted a common protocol, on the basis of the ideas of both teams and the CDC. This protocol was iteratively developed and described the collaborative process whereby the teams would create a pilot CKD surveillance system. Final approval for the common protocol was sought from the project’s steering committee.

An external advisory group consisting of members from key stakeholder organizations, including government agencies, professional societies, advocacy groups, and other national experts, was formed (see Acknowledgments). The envisioned role of the Advisory Group was to provide stakeholder input on various issues, including the importance of individual topics and measures and the evaluation of data sources (see below).

### Enumeration of Topics and Priority Measures Relevant to CKD Surveillance

With the organizational and structural tasks completed, the teams moved forward to identify relevant *topics* (broad areas important to capture in a surveillance system) and *measures* (more specific concepts within the topics) that a CKD surveillance system should encompass. Six topics to be addressed were identified: (1) burden of CKD (prevalence/incidence), (2) awareness of CKD, (3) risk factors for CKD, (4) health consequences in CKD, (5) processes and quality of care in CKD, and (6) health system capacity for CKD. Within

Table 1. Initial specific aims of the CDC CKD Surveillance System Project<sup>a</sup>

Aim	
1.	Enumerate topics relevant to CKD surveillance and identify measures within each topic
2.	Identify existing national and regional data sources that contain possible topics, measures, and indicators for CKD surveillance
3.	Evaluate each data source/topic-measure-indicator combination using available scientific evidence and achieve consensus as to which data sources should be part of a CKD surveillance system
4.	Develop a comprehensive plan for integration of all the data source/topic-measure-indicator combinations into a functional national surveillance system
5.	Assess the feasibility of integration of all the data sources into a functional national surveillance system
6.	Conduct a pilot test of the system
7.	Produce interim reports of CKD surveillance with recommendations toward the implementation of a national CKD surveillance system

<sup>a</sup>Definitions are as follows: “topics” are broad areas important to capture in a surveillance system (e.g., “burden of risk factors for CKD”); and “measures” are specific concepts within topics that are important (e.g., “prevalence of diabetes mellitus” is an important measure under the topic of “burden of risk factors for CKD”).

these topics, a comprehensive list of 136 possible measures was generated by using a modified two-step Delphi process, typically used to gain consensus on a particular subject (16). The first step involved the enumeration of possible measures under each major topic on the basis of a literature review and the opinion of experts comprising both the steering committee and advisory group. As a next step, the steering committee and advisory group members were enlisted to rate each of the possible measures for their importance and relevance to a CKD surveillance system. Measures were ranked in

importance from 1 (least important) to 5 (extremely important). Ratings from advisory group and steering committee members were standardized by multiplying by the ratio (overall group average for all measures)/(individual's average for all measures). Standardized ratings were then averaged for each measure. The top five measures from each topic area were chosen for exploration during the first phase of the surveillance system, with the additional measures reserved for future exploration. Table 2 displays the six broad topics and the top five measures within each of the topics.

Table 2. Top five measures within each topic category, as ranked by advisory group

Measure	Rating <sup>a</sup>	Rank
A. Burden of CKD (CKD incidence and prevalence)		
A.1 Prevalence of stages 1–5 CKD by eGFR (kidney function)	4.74	1
A.2 Incidence of stages 1–5 CKD by eGFR (kidney function)	4.68	2
A.3 Prevalence rates of renal replacement therapy [dialysis (stage 5D)]	4.51	3
A.4 Prevalence of kidney transplantation (stage 5T)	4.40	4
A.5 Incidence rates of renal replacement therapy [dialysis (stage 5D)]	4.34	5
B. Awareness of CKD		
B.1 Awareness of risk among diabetics	4.85	1
B.2 Awareness of risk among hypertensives	4.85	1
B.3 Knowledge of CKD risk factors	4.84	3
B.4 Awareness of risk among those with family history of CKD/ESRD	4.76	4
B.5 Awareness of CKD among those with kidney disease diagnosed by laboratory testing	4.43	5
C. Burden (incidence/prevalence) of risk factors for CKD		
C.1 Diabetes mellitus	4.84	1
C.2 Hypertension	4.84	1
C.3 Blood pressure control	4.84	1
C.4 Family history	4.64	4
C.5 Race/ethnicity	4.64	5
D. Health consequences in CKD patients		
D.1 Proportion of CKD patients moving to ESRD over time	4.85	1
D.2 All-cause mortality rates	4.56	2
D.3 Proportion of CKD patients moving stage over time	4.56	3
D.4 Progression of CKD by demographic characteristics (e.g., race/ethnicity)	4.52	4
D.5 Progression of decreased renal function by level of proteinuria	4.16	5
E. CKD processes and quality of care		
E.1 Detection of CKD in those with risk factors	4.96	1
E.2 Utilization of medications for hypertension	4.96	1
E.3 Degree of blood pressure control	4.96	1
E.4 Appropriate use of ACEIs/ARBs (e.g., for diabetics with proteinuria and for hypertensives)	4.96	4
E.5 Referral to a nephrologist by primary care physicians prior to ESRD	4.54	5
F. Health system capacity for CKD		
F.1 Reporting of eGFR	4.80	1
F.2 Adequacy of insurance coverage	4.38	2
F.3 Use of standardized creatinine	4.25	3
F.4 Transplant centers	4.08	4
F.5 Dialysis centers (hemodialysis or peritoneal dialysis)	3.99	5

ACEI, angiotensin-converting enzyme inhibitor; ARB, angiotensin receptor blocker; eGFR, estimated glomerular filtration rate.

<sup>a</sup>Of a possible maximum rating of 5 (extremely important). Tied ranks are represented, giving each measure the smallest rank possible.

The complete list of all 136 measures and their rankings is provided in the Supplemental Information.

*Identification and Feasibility Assessment of Data Sources*

In designing this CKD surveillance system, the teams considered both pre-existing and ongoing prospective data collection efforts, datasets rich in CKD-related information, and datasets procurable from the various components of the US health care system. The latter have the potential to continually provide data pertaining to CKD surveillance from large segments of the population. This approach was deemed more efficient and less costly or resource-intensive than “active” surveillance. For the surveillance system to be nationally representative, care was taken to identify data sources that covered all segments of the population (*e.g.*, children, young adults, the elderly, ethnic or racial minorities, the uninsured, etc.; see Figure 1) and could yield information on the entire spectrum of CKD, from minor impairment (stage 1) to dialysis (stage 5D) or transplantation (stage 5T), but focusing primarily on CKD before the onset of end-stage renal disease (ESRD).

Similar to the process used in the enumeration of potential measures, a modified Delphi process was invoked for the enumeration, evaluation, and subsequent prioritization of possible data sources for the surveillance system. A comprehensive list of potential data sources was first developed on the basis of Internet and literature searches and consensus within the steering committee (see Table 3 for a sample). These included national surveys, registries, population-based and prospective cohort studies, private laboratories, and health care system data. A standardized questionnaire was used to interview contacts knowledgeable about each data source to: (1) gather information about available data for the prioritized topics and measures; and (2) evaluate a data source’s potential attributes, such as availability for participation in the surveillance system, data quality, representativeness, defined denominator, timeliness (time between data collection and completed processing for disbursement), sensitivity, stability, simplicity (time and personnel

necessary for the data source to transfer data to us), and flexibility (whether the data source had the ability to add or change variables with the advent of new technology or guidelines).

*Evaluation and Selection of Data Sources*

The teams compiled and summarized the data source information, then enlisted both the steering committee and the advisory group to (1) rank the top data sources for each measure (using the top 10 measures within each broad topic), and also (2) rank the best data sources overall. These rankings allowed prioritization of the data sources for the pilot phase of the CDC CKD Surveillance System. Table 4 is a display of the top three data sources, as ranked by the steering committee and advisory group, for each of the top five measures within each topic.

Before data analysis, the teams identified possible gaps or deficiencies in the data sources, which allowed assessment of the need for exploration of other/new data sources in the future. It should be emphasized, however, that only real-time and ongoing procurement and analysis of data from these sources will enable the investigators to provide a definitive evaluation of data deficiencies.

Health care system data initially considered for inclusion in the CDC CKD Surveillance System included: (1) the Veterans’ Affairs Health System (national) data, (2) data from a regional combination of managed care plans from southeastern lower Michigan, (3) large, privately owned data warehouses, such as Medstat and Ingenix, (4) a variety of data from the Centers for Medicare and Medicaid Services (national), (5) the Indian Health Service (national), (6) the CKD Solutions Data Registry, and (7) certain laboratory data sources, such as Labcorp and Joint Venture Hospital Laboratories. Non-health care system data included: (1) national surveys, such as the NHANES and Behavior Risk Factor Surveillance System, and other surveys, such as those conducted by the National Kidney Disease Education Program; (2) screening studies, such as the Kidney Early Evaluation Program; (3) national registries, such as the US Renal Data System for CKD stage 5D and the Scientific Registry of Transplant Recipients for CKD in recipients of solid organ transplants (kidney, liver, thoracic, etc.); (4) population-based cohort studies, including Atherosclerosis Risk in Communities Study, Cardiovascular Heart Study, Multi-Ethnic Study of Atherosclerosis, Framingham Heart Study, and Coronary Artery Risk Development in Young Adults; and (5) CKD-based cohort studies, including the Chronic Renal Insufficiency Cohort Study, the Chronic Kidney Disease in Children, the Renal Research Institute Chronic Kidney Disease Study, and the African American Study of Kidney Disease and Hypertension (17–32).

*Integration of the Data Sources and Pilot Testing of the System*

We have assembled databases from a variety of the top-ranked data sources. These databases continue to be used to evaluate the top-ranked measures, using appropriate numerators and denominators. Quality control measures were performed to check data completeness and identify possible errors; where possible, questions were directed back to the source for

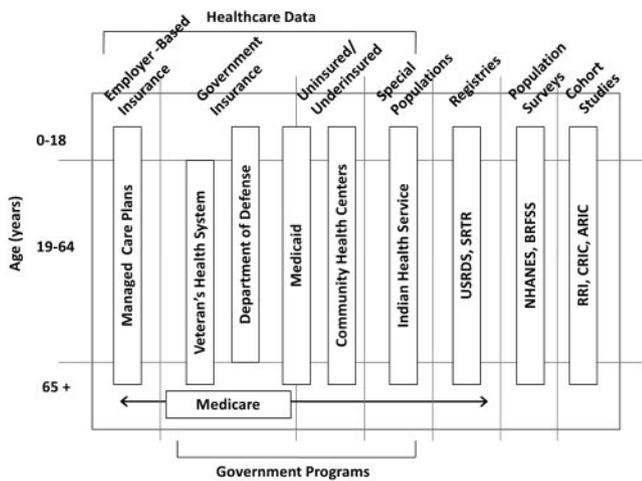


Figure 1. A conceptual approach for representing the US population via the broad variety of existing data sources available for input into the CDC CKD Surveillance System.

Table 3. Summary of key data sources useful for CKD surveillance, with their strengths and limitations

Data Source	Data Type	Topics Covered	Strengths	Limitations
NHANES	National survey	Burden of CKD; awareness, burden of risk factors for CKD; progression of CKD; health system capacity	Representative of noninstitutionalized US population; stability, simplicity, validated, comprehensive survey instruments; detailed laboratory information; data availability and data quality; clean, publicly available data for researchers	Cross-sectional survey. No longitudinal/regional data. Participation bias possible. 2-yr lag. Limited assessment of CKD awareness based on self-report. Laboratory data only in a subset. Provider data, practice patterns, or patient outcomes generally not available.
Department of Veterans' Affairs	National administrative health care data for US veterans	Burden of CKD; awareness of CKD; burden of risk factors; health consequences; processes of care; health system capacity	The only integrated national health care system in the United States; highly regarded electronic healthcare records and data warehouse; data availability and timeliness are good (6- to 8-mo lag, laboratory and medication data available, documentation of race/ethnicity fair).	Weak on representativeness because it caters almost entirely to the veteran population (predominantly male). No link to the electronic health care record.
Medicare claims data	National administrative health care data	Burden of CKD; awareness of CKD; burden of risk factors; health consequences; processes of care	Nationally representative data; large number even in a 5% random sample of claims data. Medicare Part D (prescription medications) data now available separately.	Mainly claims data. No laboratory data currently available. No link to electronic health care record. Representativeness limited to those $\geq 65$ yr of age. Timeliness: lag period of about 1–2 yr.
MCARE	Regional administrative health care data	Burden of CKD; awareness of CKD; burden of risk factors; health consequences; processes of care	Regionally representative data from a private health care plan in southeast Michigan. Willingness to participate was high. Useful for the pilot/developmental phase of the CKD surveillance system. Timeliness: approximately 1-yr lag.	Representativeness limited to the employed relatively younger population in a small region. No information on race/ethnicity. Ceased to be in existence as of 2007. Availability of laboratory data incomplete. No link to electronic health care record.

Table 3. (Continued)

Data Source	Data Type	Topics Covered	Strengths	Limitations
Scientific Registry of Transplant Recipients	National registry of all solid organ transplantation in the United States	Burden of CKD; burden of risk factors; health consequences; processes of care; health system capacity	Nationally representative, comprehensive registry on all solid organ transplantation in the United States. Availability: data use agreements necessary. Data quality: clean data available to researchers. Timeliness: acceptable 1-yr lag.	Laboratory data pertinent to CKD not always captured and somewhat differently collected for different organ transplants. Proteinuria information not available. Detailed medication data not available. No link to electronic health care record.
United States Renal Data System	National Registry all US ESRD patients	Burden of CKD; burden of risk factors; health consequences; processes of care; health system capacity	A nationally representative ESRD registry, although chapter on CKD increasingly detailed. Data availability for data on ESRD is excellent.	Mostly ESRD data. CKD databases not available to researchers. Timeliness: 1- to 2-yr lag.
Chronic Renal Insufficiency Cohort Study	Prospective cohort study	Health consequences; processes of care	Specifically designed to study CKD progression and health consequences, specifically cardiovascular disease. Will significantly enrich literature pertaining to CKD.	Subject to finite timeline. Mostly captures a referred population of adults with CKD. Representativeness: not nationally representative. Subject to participation bias. Resource intensive. Timeliness: significant and variable lag.
Atherosclerosis Risk In Communities Study	Prospective cohort study	Burden of CKD; burden of risk factors; health consequences; processes of care	An example of a large prospective cohort study, where data are available to researchers on request.	Finite timeline. Representativeness: not national. Participation bias. Not primarily designed for study of CKD. Timeliness: significant and variable lag. Resource intensive.

Table 4. Top three data sources for each of the top five measures

Measure	Data Source		
	First-Ranked	Second-Ranked	Third-Ranked
A.1 Prevalence of stages 1–5 CKD by eGFR (kidney function)	NHANES	JVHL/VAAAHS (tie)	—
A.2 Incidence of stages 1–5 CKD by eGFR (kidney function)	CRIC	ARIC/Medstat/ VAAAHS (tie)	—
A.3 Prevalence rates of renal replacement therapy [dialysis (stage 5D)]	USRDS	Medstat	VAAAHS
A.4 Prevalence of kidney transplantation (stage 5T)	SRTR	USRDS	BCBS/Medstat (tie)
A.5 Incidence rates of renal replacement therapy [dialysis (stage 5D)]	USRDS	CMS/VAAAHS (tie)	BCBS
B.1 Awareness of risk among diabetics	BRFSS	NKDEP	KEEP
B.2 Awareness of risk among hypertensives	BRFSS	NKDEP	KEEP
B.3 Knowledge of CKD risk factors	KEEP/NKDEP (tie)	—	—
B.4 Awareness of risk among those with family history of CKD/ESRD	KEEP/NKDEP (tie)	—	—
B.5 Awareness of CKD among those with kidney disease diagnosed by laboratory testing	NHANES	KEEP	MESA/CHS (tie)
C.1 Diabetes mellitus	NHANES	CMS	VAAAHS
C.2 Hypertension	NHANES	CMS	BCBS
C.3 Blood pressure control	NHANES	MCARE	CKD Solutions/IHS
C.4 Family history	BRFSS	CKD Solutions	IHS
C.5 Race/ethnicity	NHANES	CMS	VAAAHS
D.1 Proportion of CKD patients moving to ESRD over time	CMS	BCBS	CRIC
D.2 All-cause mortality rates	CMS	NHANES	USRDS
D.3 Proportion of CKD patients moving stage over time	CMS	CRIC	VAAAHS
D.4 Progression of CKD by demographic characteristics (e.g., race/ethnicity)	CRIC	CMS	CKD Solutions/Medstat (tie)
D.5 Progression of decreased renal function by level of proteinuria	CRIC	VAAAHS	CKD Solutions
E.1 Detection of CKD in those with risk factors (see B)	CMS	BCBS	VAAAHS
E.2 Usage of medications for hypertension	NHANES	VAAAHS	BCBS
E.3 Degree of blood pressure control	NHANES	CKD Solutions	IHS
E.4 Appropriate use of ACEIs/ARBs (e.g., for diabetics with proteinuria and for hypertensives)	NHANES	BCBS/CKD Solutions (tie)	—
E.5 Referral to a nephrologist by primary care provider prior to ESRD	CMS	USRDS	VAAAHS
F.1 Reporting of eGFR	LabCorp	JVHL	NKDEP/VAAAHS (tie)
F.2 Adequacy of insurance coverage	NHANES	BCBS/Medstat	—
F.3 Use of standardized creatinine	LabCorp	VAII	—
F.4 Transplant centers	SRTR	VAII	—
F.5 Dialysis centers (hemodialysis or peritoneal dialysis)	MCARE	BCBS/VAAAHS	—

AASK, African American Study of Kidney Disease and Hypertension; ARIC, Atherosclerosis Risk in Communities Study; BCBS, Blue Cross Blue Shield; BRFSS, Behavioral Risk Factor Surveillance System; CARDIA, Coronary Artery Risk Development in Young Adults; CHS, Cardiovascular Health Study; CKD Solutions, CKD Solutions Data Registry; CKID, Chronic Kidney Disease in Children; CMS, Centers for Medicare and Medicaid Services; CRIC, Chronic Renal Insufficiency Cohort; FHS, Framingham Heart Studies; GLHP, Great Lakes Health Plan; HAP, Health Alliance Plan; IHS, Indian Health Service; JVHL, Joint Venture Hospital Laboratories; KEEP, Kidney Early Evaluation Program; Labcorp, Labcorp Laboratories; MESA, Multi-Ethnic Study of Atherosclerosis; NHANES, National Health Examination and Nutrition Survey; NKDEP, National Kidney Disease Education Program; RRI-CKD, Renal Research Institute Chronic Kidney Disease Study; SRTR, Scientific Registry of Transplant Recipients; USRDs, US Renal Data System; VAAAHS, Veterans' Affairs Ann Arbor Health System; and VAII, Veterans Affairs II (interview conducted with a separate national Veterans' Affairs researcher).

resolution. In addition to primary data analysis of pre-existing data, previously published data germane to CKD surveillance were incorporated, with due permission from authors and publishers. The pilot testing of the surveillance system methodology has thus far resulted in the production of a report (see below) detailing the results of the analyses of each measure from the multiple data sources.

## Continuing and Future Work

### *Dissemination of Findings*

Regular submission of reports will be an integral part of this project. In the very near future, these reports will be made publicly available on the CDC web site. An interim report of the pilot and feasibility phase of the CDC CKD Surveillance System (October 2006 to September 2008) was submitted to the CDC in September 2008. A 2009 report containing new and updated information is currently underway. Although the reports are not yet publicly available in their entirety, the executive summary of the 2008 report has been made available on request to either of the CDC CKD Surveillance System teams or the CDC, and it has been appended to this article (Supplemental Information).

A CDC CKD Surveillance web site is currently under development in collaboration with the CDC, and it is considered an important task in the current phase of this project. The information contained on the CDC web site will provide feedback to the medical and research communities at regular intervals by the detailed interactive display of CKD-related data and trends in the United States. The CDC CKD Surveillance web site will also support the intergovernmental agency development of a CKD fact sheet. The fact sheet is intended to be a summary of salient information pertaining to CKD, intended primarily for health care professionals, policymakers, the media, and the public. The CDC is leading the development of the fact sheet and plans to release it at regular intervals.

### *Project Significance, Successes, and Challenges*

The primary project goal remains the establishment of a dedicated, comprehensive, and ongoing prospective surveillance system for CKD for the United States, focusing initially on data from a variety of currently existing data sources that either singly or in combination represent the US population. Dissemination of the findings is intended to increase awareness of CKD and its importance as a major public health problem and stimulate multiple stakeholders to develop a comprehensive action plan for health improvement. Data on incidence, prevalence, and risk factors collected by the CDC CKD Surveillance System may prompt researchers and health care providers to screen those at risk for CKD and to actively seek out those already affected by, but unaware of, the disease. Providers may find this information useful to evaluate the risk profile of patient populations, as well as risk stratify their patient populations to make appropriate recommendations for targeted primary and secondary prevention. Analysis of health care data may assist researchers and clinicians in identifying optimal practice patterns to guide practice as well as generate new hypotheses, kindling new research. Laboratory and pharmacy

data from health care systems may allow observation of diagnostic and therapeutic practice patterns in both those with risk factors and those already diagnosed with CKD. Together, these elements would allow comprehensive tracking of all aspects of CKD, including current health care usage and predicting implications for the future.

During the pilot and implementation stages of the project, major achievements included the establishment of a common protocol for national CKD surveillance, the installation of a multidisciplinary steering committee and advisory group, development and prioritization of key topics and multiple potential measures related to CKD, the evaluation and prioritization of multiple data sources, data analyses, and the successful development and submission of the initial report of the surveillance system to the CDC.

Major challenges to the project have included the identification and acquisition of datasets that allow the long-term monitoring of CKD and its care in the United States. Team members are continuing to test future data procurement from currently participating data sources while exploring strategies for successful integration of data from the disparate sources; *e.g.*, by testing the feasibility of calculating US population-based estimates from individual data sources and/or by attempting to create a combined database derived from disparate health care system data sources.

Team members are also continually assessing new data sources for inclusion in the system. The system seeks to be sensitive and flexible to new advances in the field and adaptive to developing newer evidence-based strategies for surveillance. New evidence-based measures will be considered for inclusion on the basis of recent advances in CKD, such as changes in definitions, laboratory technology, pharmacology, clinical practice guidelines, or the identification of novel risk factors or methods of estimating/measuring kidney function. As a final challenge, the seamless integration of the CDC CKD Surveillance System with other chronic disease surveillance systems remains a high priority. A number of organizations, both national and regional, are committed to the task of addressing the problem of CKD in the United States. Examples include the US Renal Data System, the National Kidney Foundation, the National Kidney Disease Education Program, the National Diabetes Surveillance System, and the Centers for Medicare and Medicaid Services. Interagency agreements between several national organizations currently exist, and regular interaction between the key stakeholders is critical not only for developing consensus guidelines but also implementing public health action to decrease CKD burden in the United States.

## Summary and Conclusions

In summary, we have described efforts to create a national CKD surveillance system. Six broad topics and several measures were identified and prioritized for CKD surveillance. A pilot and feasibility phase of obtaining, analyzing, and synthesizing data obtained from a variety of data sources is currently ongoing, along with preparations for the development and regular production of an annual report of the CDC CKD Surveillance System, a CKD fact sheet for widespread dissemination, and a regularly updated

and interactive project web site. It is envisioned that this dedicated national CKD Surveillance System will be a readily available and useful resource for health care providers, public health authorities, and policy makers alike. In the future, greater use of active surveillance methodologies complementing the current approach may be considered. Advances in health information technology are very likely to have a major impact on the surveillance system of the future. We believe that this CDC CKD Surveillance System will be vital for an ongoing assessment of the national CKD burden and its impact on the population at large as well as the health care system. We hope that it will lay the foundation for widespread efforts toward primary prevention, earlier detection, and implementation of optimal disease management strategies, with resultant decreased rates of CKD progression and lowered morbidity and mortality.

#### CDC CKD Surveillance Team

The entire study group consists of: Centers for Disease Control and Prevention: Desmond Williams, Mark Eberhardt, Kristina Ernst, Nicole Flowers, Linda Geiss, Regina Jordan, Nilka Rios Burrows, Juanita Mondesire, Bernice Moore, Gary Myers, Meda Pavkov, Deborah Rolka, Susan Hailpern, Sharon Saydah, Anton Schoolwerth, Rodolfo Valdez, and Paul Eggers (National Institutes of Health); University of California San Francisco/Johns Hopkins University: Neil Powe (Principal Investigator), L. Ebony Boulware, Josef Coresh, Deidra Crews, Andrew Levey (Tufts Medical Center and Tufts School of Medicine), Edgar R. Miller, III, Laura Plantinga, and Lesley Stevens (Tufts Medical Center and Tufts School of Medicine); University of Michigan: Rajiv Saran (Principal Investigator), Philip Boonstra, Brenda Gillespie, Elizabeth Hedgeman, William Herman, Kassandra Messer, Bruce Robinson (Arbor Research Collaborative for Health), Friedrich Port (Arbor Research Collaborative for Health), Vahakn Shahinian, Randall Webb, Jerry Yee (Henry Ford Health System), Meggy Yin (Arbor Research Collaborative for Health), and Eric Young (Department of Veterans' Affairs).

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#### Disclosures

None.

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