

CKD as a Model for Improving Chronic Disease Care through Electronic Health Records

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Abstract

Electronic health records have the potential to improve the care of patients with chronic medical conditions. CKD provides a unique opportunity to show this potential: the disease is common in the United States, there is significant room to improve CKD detection and management, CKD and its related conditions are defined primarily by objective laboratory data, CKD care requires collaboration by a diverse team of health care professionals, and improved access to CKD-related data would enable identification of a group of patients at high risk for multiple adverse outcomes. However, to realize the potential for improvement in CKD-related care, electronic health records will need to provide optimal functionality for providers and patients and interoperability across multiple health care settings. The goal of the National Kidney Disease Education Program Health Information Technology Working Group is to enable and support the widespread interoperability of data related to kidney health among health care software applications to optimize CKD detection and management. Over the course of the last 2 years, group members met to identify general strategies for using electronic health records to improve care for patients with CKD. This paper discusses these strategies and provides general goals for appropriate incorporation of CKD-related data into electronic health records and corresponding design features that may facilitate (1) optimal care of individual patients with CKD through improved access to clinical information and decision support, (2) clinical quality improvement through enhanced population management capabilities, (3) CKD surveillance to improve public health through wider availability of population-level CKD data, and (4) research to improve CKD management practices through efficiencies in study recruitment and data collection. Although these strategies may be most effectively applied in the setting of CKD, because it is primarily defined by laboratory abnormalities and therefore, an ideal computable electronic health record phenotype, they may also apply to other chronic diseases.

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Introduction

Electronic health records (EHRs) that enable efficient and secure exchange of health care data among providers, patients, health care administrators, and public health officials have the potential to improve clinical care for a variety of chronic conditions. Well designed EHR systems can facilitate improved care for patients with chronic diseases across all elements of the Chronic Care Model, including clinical information systems (e.g., identifying patients and improving continuity of care), decision support for providers, delivery system design (e.g., multidisciplinary teams and provider collaboration), and patient self-management support (Figure 1) (1). Standardized and accessible EHR systems can also improve our understanding of chronic diseases by providing rich data for observational studies, identifying potential patients for research, and enabling national surveillance systems.

Because of this potential for improved care, the Health Information Technology for Economic and Clinical Health Act established the Medicare and Medicaid EHR Incentive Programs to encourage the widespread implementation and use of EHRs (2). Eligible providers that show that they have met the criteria for meaningful use of certified EHR technology may qualify for incentive payments under

Medicare and Medicaid. This is one of many factors that has resulted in a 3-fold increase in the number of clinics and hospitals using EHRs between 2001 and 2011 (3). As EHR use becomes more widespread, it is important to recognize and capitalize on the potential of EHRs to improve the care of patients with chronic conditions. More integrated EHR data may not only help provide direct clinical benefits but also, greater data integration could simultaneously support secondary public health and research objectives (i.e., disease registries and pragmatic clinical trials) that could increase disease knowledge and ultimately, improve patient care as well (4). It is also important to acknowledge some of the unintended consequences of EHRs—such as increased work tasks associated with computerized order entry, fragmentation of data, loss of communication, and clinical decision support that may be too rigid, include outdated content, and lead to alert fatigue—that need to be minimized by thoughtful design and implementation (5,6).

CKD: A Unique Condition to Show the Potential of EHRs in Chronic Disease Care

CKD represents a unique condition that may show the potential of EHRs to improve chronic disease care for several reasons.

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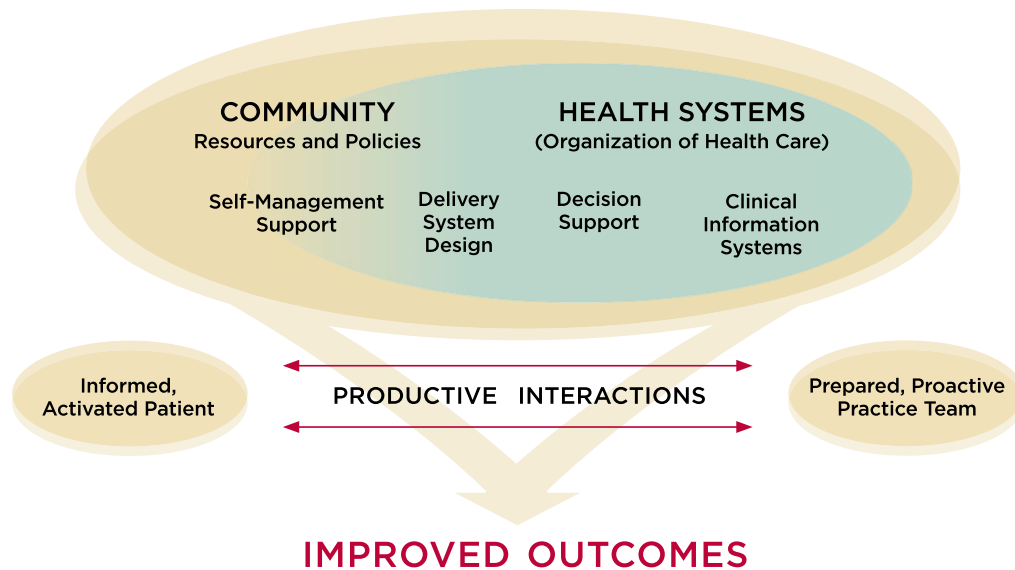
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How HIT Can Improve CKD Care



<p>COMMUNITY</p> <ul style="list-style-type: none"> • Conduct CKD surveillance <ul style="list-style-type: none"> - Identify high-need/underserved populations - Inform policy change - Target CKD care interventions • Implement virtual communities of care • Reach remote patients via telemedicine 	<p>HEALTH SYSTEMS</p> <ul style="list-style-type: none"> • Identify patients for research • Track achievement of CQM goals <ul style="list-style-type: none"> - Incentivize delivery of quality CKD care • Identify effective CKD care processes <ul style="list-style-type: none"> - Develop improvement strategies
<p>Self-management support</p> <ul style="list-style-type: none"> • Provide patients with information about their kidney function, comorbidities, and medications • Support patients' role in CKD care <ul style="list-style-type: none"> - Provide CKD patients with educational/motivational information - Support patients in day-to-day decisions • Transfer information between patients & providers <ul style="list-style-type: none"> - Patient access to in-office test results - Clinician access to home-based test results 	<p>Clinical Information Systems</p> <ul style="list-style-type: none"> • Conduct care planning for CKD patients <ul style="list-style-type: none"> - Track CKD patients within health systems - Identify patients needing additional care - Monitor performance/quality improvement - Deliver CKD guideline-directed care reminders • Collect feedback on existing care processes <ul style="list-style-type: none"> - Track errors in CKD care - Identify opportunities to improve care delivery • Develop individualized treatment plans <ul style="list-style-type: none"> - Coordinate care between CKD patients & health care team - Involve patients in decision-making
<p>Delivery System Design</p> <ul style="list-style-type: none"> • Define team roles & distribute tasks across CKD care team <ul style="list-style-type: none"> - Refer to specialists (e.g., nephrologists, dietitians) • Plan patient visits <ul style="list-style-type: none"> - Ensure patients receive recommended care and regular follow-up • Improve continuity of care <ul style="list-style-type: none"> - Share patient data across providers/settings • Automate CKD care protocols <ul style="list-style-type: none"> - Flowsheets with consolidated CKD data 	<p>Decision Support</p> <ul style="list-style-type: none"> • Provide access to evidence-based CKD guidelines <ul style="list-style-type: none"> - Help clinicians & patients make informed decisions • Integrate specialist expertise into primary care

Figure 1. | How health information technology (HIT) can improve CKD care. Potential benefits to appropriate incorporation of CKD-related data in electronic health records within the context of the Chronic Care Model (1). CQM, continuous quality management.

CKD Is a Common and Growing Clinical Problem in the United States, Providing an Opportunity to Improve Care for Many Americans

More than 20 million Americans ages 20 years old and older may have CKD (7). In 2009, the US Renal Data System (USRDS) estimated that the prevalence of CKD had increased by 20%–25% over the preceding decade (8). The current diabetes and obesity epidemics are expected to fuel additional growth. Because of the significant burden of CKD, improved performance and interoperability of data related to kidney health within and across EHR systems have the potential to improve the health of millions of Americans.

Current CKD Care Is Suboptimal and Could Benefit from Effective Use of EHRs

The care of patients with CKD is often inconsistent with published guidelines (9–11). CKD and its related complications often go unrecognized and untreated, in part because patients with CKD are asymptomatic until late stages, high-risk individuals are not always appropriately screened, and results may be misinterpreted (12). Few patients with CKD are appropriately monitored for metabolic complications (13), and over one half of patients with CKD have BP above current treatment targets (10,14). In addition, >70% of patients who progress to ESRD start dialysis with catheters, which are associated with increased morbidity and mortality compared with fistulas and grafts (15). EHRs have the potential to improve the care of such patients with CKD by facilitating earlier identification and appropriate management through tracking of processes, provider reminders, and decision support (16). After being developed for CKD, such tools could be adapted for other chronic conditions. For example, components of clinical decision support systems focused on medication monitoring and dose adjustment among patients with CKD may be adapted for use among patients with liver disease and hematologic conditions.

CKD and Its Associated Conditions Are Defined Primarily by Objective Data That Could Be Incorporated or Better Structured within EHRs with Relative Ease

CKD is primarily defined by laboratory abnormalities and may be the prototypical computable EHR phenotype (that is, a disease identified using EHR data) (17). Much of the objective data related to CKD and its complications and comorbidities is already incorporated into many EHRs. However, more complete labeling of test names and units (18) with universal codes, such as Logical Observation Identifiers Names and Codes (LOINC) (19) for laboratory results, is needed to optimize their use. Because CKD comorbidities and complications (*e.g.*, BP, A1C, cholesterol, and urine albumin-to-creatinine ratio) are relevant to numerous chronic conditions (*e.g.*, heart disease and diabetes), such optimization of data would be broadly beneficial to chronic disease care. Thus far, subjective elements critical to optimal CKD care, such as renal replacement modality choice, have been more challenging to capture uniformly and have not yet been incorporated into most EHRs.

Optimal CKD Care Requires Collaboration by a Broad and Diverse Team of Health Care Professionals across Numerous Settings, Which Could Be Facilitated by More Functional EHR Interoperability

Most care for patients with CKD is provided in the primary care setting. However, optimal CKD care, especially in more advanced stages, requires active collaboration with a broad range of providers, including nephrologists, pharmacists, nurses, dietitians, and allied health professionals. These providers often work in diverse settings, including inpatient and outpatient facilities, emergency departments, extended and long-term care facilities, pharmacies, and dialysis facilities. Members of the entire CKD care team need to have accurate and timely information to appropriately assess care needs, prescribe or adjust medications, optimize patient education, and ensure a coordinated transition to RRT if necessary (20). In addition to supporting interprovider and intersite collaboration for CKD, improved interoperability and collaboration tools within and across EHR systems have the potential to enhance team-based care for a variety of conditions.

CKD Is Clinically Significant, and Incorporation of CKD Data into EHRs Will Facilitate Identification of a High-Risk Patient Population

CKD is often a sentinel disease, heralding increased risk for hospitalizations, cardiovascular events, and all-cause mortality (21). Effective implementation of CKD data into EHRs will enable providers to more easily identify this high-risk patient population for targeted care management programs that may reduce the increased risk for adverse outcomes associated with CKD (22).

Improving EHRs to Facilitate Quality Care for Patients with Chronic Conditions

Given the potential benefit of greater EHR use to improve care for patients with CKD, the National Kidney Disease Education Program has established a Health Information Technology Working Group (23). The goal of the working group is to enable and support the widespread interoperability of data related to kidney health among health care software applications to optimize CKD detection and management. A subset of the working group, consisting of experts in bioinformatics, nephrology, population health, and clinical research, met over the course of the last 2 years to identify general features needed within EHR systems to improve care for patients with CKD; the working group then identified ways in which CKD data, after appropriately incorporated within EHRs, could be used to improve the care of patients with CKD. This paper outlines general recommendations for features needed to facilitate:

Optimal care of individual patients through improved and intuitive provider- and patient-facing interfaces as well as secure access for both patients and providers to all clinical information, regardless of where the data were collected. Clinical quality improvement through quality measurement and implementation of population management programs. National CKD surveillance to improve public health through broader availability of population-level CKD data.

Research to improve CKD management practices, such as observational studies, comparative effectiveness research, and enhanced design and implementation of clinical trials through efficiencies in study recruitment and data collection.

A number of organizations have implemented various EHR-based interventions and registries (Table 1). Unfortunately, the majority of these early efforts have been isolated to single institutions, required significant resources to develop, and have not been adopted by other organizations. Navaneethan *et al.* (24) outline potential applications of EHRs for CKD identification and management within an individual health care system. This paper aims to build on that discussion by presenting general goals and a framework for more widespread implementation and use of these evolving tools and resources.

EHRs Should Incorporate CKD-Related Data as Structured Data Using Standard Code Systems and Units to Enable Identification and Effective Management across the Entire Disease Course

For the purposes of incorporation into EHRs, CKD-related data may be most effectively categorized into three types (Table 2).

- (1) Laboratory data required to diagnose CKD, evaluate its severity, monitor progression, and identify appropriate treatment. Required data include measures of kidney function (*i.e.*, serum creatinine, corresponding eGFR, and method of estimation) and kidney damage (*i.e.*, quantitative assessment of urine albumin excretion, such as urine albumin-to-creatinine ratio) (25). Meaningful use stage 2 required that EHRs incorporate at least 55% of their numeric and qualitative tests as structured data as of November of 2014 (26); meaningful use stage 3 will likely strengthen this requirement.
- (2) Data related to CKD risk factors, complications, comorbidities, and treatments, which are critical to determine the etiology of CKD, optimize treatment to prevent or delay progression (27), dose medications requiring adjustment for renal function, and reduce the risk of avoidable AKI (28,29). These data are also available in most EHRs in structured and unstructured formats and include the following items.
 - Diagnoses, such as diabetes mellitus, hypertension, dyslipidemia, anemia, and cardiovascular, cerebrovascular, and peripheral vascular disease (stage 1 meaningful use core objective).
 - Clinical and laboratory results, such as BP, glucose, lipids, hemoglobin, urinalysis, potassium, bicarbonate, transferrin saturation index, ferritin, calcium, phosphorus, and parathyroid hormone.
 - Prescription and over-the-counter medications are almost universal and use standard coding systems, such as RxNorm (stage 1 meaningful use core objective).
 - Documentation of nephrology referral, which is essential both to ensure appropriate preparation for RRT and because early referral may reduce mortality in those who progress to ESRD (30–32).
- (3) Patient education and preferences and planning for ESRD. Unlike the first two categories of CKD-related data, this final category is not available in most EHRs and often needs to be obtained from patients; collection of these

data needs to be carefully planned, so that it can be converted to structured data to support applications, such as decision support. This category includes data related to the following items.

- Patient education, such as attending nutrition or treatment options classes.
- Preferences regarding dialysis modality, vascular access, and transplantation.
- Patient-reported outcomes, such as quality of life or functional status.
- ESRD planning data with regard to vascular access (*i.e.*, vein mapping, surgery referral, access placement date, and previous complications and interventions), evaluation for peritoneal dialysis, and/or transplant evaluation and listing.

For optimal management of CKD, all three data categories should be incorporated within EHRs using standard code systems and units (18). Challenges to implementation include legacy local coding systems and implementation of EHRs that is highly variable and customized for each provider organization (33).

CKD-Related Data in EHRs Should Be Readily Available and Easily Accessible for Patients and Providers

Although data in the first two categories are included in most EHRs, they are frequently stored in formats that do not allow easy access by patients and providers. CKD-related data should be stored in structured, standard formats incentivized by the EHR Incentive Program's meaningful use criteria. Although such formats have been incorporated into many EHRs, there is room for improvement. For example, some EHRs continue to store BP data as a text field as systolic value/diastolic value. Although the EHR Incentive Program meaningful use encourages the use of standard LOINC codes (19) for identifying laboratory results, these are only beginning to appear within EHRs, and EHRs do not consistently use the standard units of measure (Unified Code for Units of Measure) (18) that are recommended by Health Level 7.

Even when data are appropriately stored, it can be time-consuming to manually search multiple sections of the EHR to obtain necessary CKD-related data during a patient visit (34). EHRs could offer provider-facing flow sheets to display all important CKD-related data in one location. These flow sheets could be embedded with decision support tools, clinical reminders, and links to supporting references. Furthermore, providers should have access to customizable displays of longitudinal data to allow critical monitoring of trends and disease progression. Patients should also have access to these flow sheets with consolidated CKD-related data to facilitate self-management support.

EHRs Should Support Exchange of CKD-Related Information across Health Care Settings

Information exchange across health care settings and between providers is critical to providing optimal care for patients with CKD, but records are currently fragmented. For example, clinical data from dialysis facilities are not

Table 1. Sample of health information technology efforts in CKD

Source	EHR	Tool(s)	Study Design	Participants (N)	Intervention	Outcome	Comments
Navaneethan <i>et al.</i> (53)	Epic Systems Corporation	CKD registry	Description of development and validation of EHR-based CKD registry	57,276 patients with CKD	EHR-based identification of patients with CKD on the basis of two eGFR values <60 ml/min per 1.73 m ² at least 90 d apart and/or kidney disease-related ICD 9 codes	Availability of an EHR-based CKD registry (including demographic, clinical, and laboratory details) for research and PHM	Although this registry provides data on a significant number of patients, it is limited to a single open health system and had to be created outside the system's EHR; ongoing efforts to facilitate HIE across this system and others in northeast Ohio will improve patient management and research data (24); continued expansion of HIE in CKD will support broader CKD surveillance, such as CDC efforts

Table 1. (Continued)

Source	EHR	Tool(s)	Study Design	Participants (N)	Intervention	Outcome	Comments
Lee and Forbes (20)	Kaiser Permanente HealthConnect	CKD population management database	Observational study with historical controls	100,000 members of Kaiser Permanente Hawaii with CKD	EHR-based identification and risk stratification of patients with CKD on the basis of eGFR and UACR; unsolicited referral recommendations to primary care providers for high-risk patients with CKD; unsolicited consultations to primary care providers for patients with CKD who could benefit from improved medical management; nephrology review of incoming referrals with recommendations to retract referral in low-risk patients	CKD population management by nephrology reduced late referrals and referrals of low-risk patients with CKD and increased referrals of high-risk patients, allowing nephrologists to target patients at greatest need	Lack of comparable EHR systems limits the generalizability of such efforts in health care settings with less robust EHRs
Rutkowski et al. (54)	Southern California Kaiser Permanente EHR	CKD staging and population management	Description of EHR-based CKD staging and population management program; observational study with historical controls	2.5 million adult patients; 72,005 (2.9%) identified for CKD population management	EHR-based staging algorithm developed; care management summary sheet with the EHR; electronic best practice alerts	Increased percentage of patients with high-risk CKD seen by a nephrologist in the last year (20%–24%); only 45% of patients used a catheter for their first hemodialysis	Good example of population management enabled by a robust EHR within an integrated health system; lack of a formal analysis limits conclusions regarding the effect of the program

Table 1. (Continued)

Source	EHR	Tool(s)	Study Design	Participants (N)	Intervention	Outcome	Comments
Mendu <i>et al.</i> (22)	Brigham and Women's Longitudinal Medical Record	CDSS: CKD checklist	Prospective, nonrandomized study	105 in intervention arm; 263 in control arm	Implementation of an evidence- and guideline-based CKD checklist into a primary care EHR by a study investigator or nursing staff	The CKD checklist improved adherence to CKD management guidelines, including glucose control, ACEI/ARB use, NSAID avoidance, cholesterol management, etc.	Checklist required manual entry of relevant information by a study investigator or nursing staff member who also emailed a reminder to providers weekly; ideally, these tasks would be automated
Wilson <i>et al.</i> (55)	Sunrise (Eclipsys) and Medview	CDSS: automated AKI alert	Randomized, controlled trial	1201 in alert group; 1192 in usual care group	Implementation of a computerized algorithm to track changes in serum creatinine values in real time during the hospital stay and alert clinicians of AKI presence by a text page	The electronic alert system for AKI did not improve clinical outcomes (including change in creatinine, dialysis, or death) among hospitalized patients or reduce exposure to contrast, aminoglycosides, or NSAIDs	The electronic alerts could have been improved if they (1) were provided as part of clinical workflow, (2) included recommendations, and (3) were provided at the time and location of decision making (58)
Field <i>et al.</i> (56)	Meditech MAGIC	CDSS: alerts	Cluster randomized, controlled trial	274 alerts in intervention arm; 257 hidden alerts in control arm	Implementation of a CDSS for improving dose and frequency of medication orders for long-term care facility residents with decreased kidney function	CDSS implementation improved medication administration frequency, reduced order rate of drugs that should be avoided, and increased serum creatinine orders when results were missing	Improvements were modest (63% of alerted orders were appropriate in the intervention units versus 52% in the control units); short duration of study precludes assessment of whether providers would develop alert fatigue

Table 1. (Continued)

Source	EHR	Tool(s)	Study Design	Participants (N)	Intervention	Outcome	Comments
Barnes <i>et al.</i> (57)	Not specified.	CKD identification	Observational study with pre/post analysis	146 patients	EHR-based identification of patients with CKD on the basis of eGFR calculated from recorded serum creatinine; pharmacist review of EHR to assess medical management and drug dosing	Pharmacist review improved medication use (e.g., increased ACEI/ARB use) and safety (e.g., medication dose adjustment) among identified patients with CKD	Pairing this PHM effort with implementation of an appropriate CDSS may improve medication use and safety without requiring time-intensive chart review by pharmacists
Cooney <i>et al.</i> (59)	VA CPRS	CKD registry external to EHR	Randomized, controlled trial	1070 intervention arm; 1129 usual care	CKD registry to identify patients; phone-based pharmacist intervention; pharmacist-PCP collaboration; patient education	Multifactorial intervention increased adherence to CKD guidelines and increased the number of antihypertensive medications among patients with poorly controlled BP but did not improve BP control	Example of a randomized, controlled trial enabled by an existing CKD registry; pharmacist implementation of a CKD care management protocol was effective

EHR, electronic health record; VA CPRS, Veterans Affairs Computerized Patient Record System; CDSS, clinical decision support system; ICD, International Classification of Diseases; UACR, urine albumin-to-creatinine ratio; PCP, primary care provider; PHM, population health management; ACEI, angiotensin-converting enzyme inhibitor; ARB, angiotensin receptor blockers; NSAID, non-steroidal anti-inflammatory drug; HIE, health information exchange; CDC, Centers for Disease Control and Prevention.

Category and Examples	Clinical Use
CKD defining eGFR Urine albumin excretion	Identify patients with CKD; assess severity of CKD
Risk factors for initiation and progression of CKD Diabetes Hypertension	Assess etiology; slow progression of CKD
Comorbidities Cardiovascular, cerebrovascular, and peripheral vascular disease Dyslipidemia Psychiatric illness	Manage important comorbidities
Complications Anemia Hyperkalemia Metabolic acidosis Hyperphosphatemia Secondary hyperparathyroidism	Evaluate and monitor complications of CKD
Medications ACEI/ARB Gabapentin NSAIDs	Identify medications that are indicated for patients with CKD, require monitoring or dose adjustment, and should be avoided
ESRD-related data Preference for RRT modality Dialysis access Transplant status and donor availability	Enhance shared decision-making regarding modality; improve rate of appropriate vascular access use; appropriate transplant referrals

ACEI, angiotensin-converting enzyme inhibitor; ARB, angiotensin receptor blockers; NSAID, non-steroidal anti-inflammatory drug.

typically integrated with the health records of other providers. With appropriate safeguards to protect patient privacy, information exchange could be expanded, so that CKD data could be shared between providers and across care settings to improve continuity of care, and, potentially, reduce costs (35). For example, readily available dialysis prescription and recent laboratory data could lead to more appropriate and efficient care of hospitalized patients. In addition, eGFR could be included as part of electronic prescriptions to aid pharmacist verification of medication dosing and avoidance of nephrotoxic agents. Many technical and regulatory challenges, such as incompatibility across EHR systems and compliance with Health Insurance Portability and Accountability Act guidelines, remain before we can fully realize such potential.

EHRs Could Enable Use of CKD-Related Data for Measuring and Improving Quality of Care

Health care providers and hospital administrators who strive to improve performance (*e.g.*, access to care, quality of care, and efficiency) need to be able to identify and track patients with CKD within their population who are not receiving recommended care. EHRs could be configured to allow individual providers and health care delivery organizations to search for patients using CKD-related data and develop CKD registries. Quality dashboards could aggregate and display all CKD-related population data to allow providers to actively manage panels of patients,

track achievement of continuous quality management goals, and better coordinate care with other specialties. Although CKD registries and other EHR tools alone are likely not sufficient on their own to improve the quality of CKD care (36,37), CKD registries could be used by quality improvement teams to help identify patients for targeted interventions, such as patients with significantly elevated BP or those with severe CKD not yet referred to nephrology. Obstacles to developing functional CKD registries include the underlying data structure of many EHRs, difficulty in identification of important comorbidities and medications, inability to capture important processes, such as referral for CKD education, and lack of documentation of patient preferences for treatment (*i.e.*, RRT modality).

After established, CKD registries could also facilitate reporting on existing quality measures for patients with CKD that are endorsed by Healthy People 2020 and the National Quality Forum (NQF) (38). These include treatment with angiotensin-converting enzyme inhibitors or angiotensin receptor blockers for patients with nondiabetic nephropathy (NQF 0621), treatment with angiotensin-converting enzyme inhibitors/angiotensin receptor blockers for patients with diabetes and hypertension (NQF 0546), and control of BP to <140/90 mmHg (NQF 0018). These measures must be specified as eMeasures for consistent use across different EHR technologies.

EHRs Could Enable Use of CKD-Related Data to Facilitate CKD Surveillance and Improve Public Health and Health Care Planning

Public health efforts are necessary to understand the full burden of CKD across different communities and track the progress of efforts to reduce this burden through enhanced prevention, detection, and management. Improvements in CKD care could be facilitated through exploration of local, regional, socioeconomic, cultural, medical, and treatment disparities, which has been done in ESRD through the USRDS. A better understanding of these disparities is also important given the disproportionate burden of CKD among minorities and underserved populations (39).

The efforts of the Centers for Disease Control and Prevention (CDC) to establish a National CKD Surveillance System have been limited by the lack of national data (40). Early work by the CDC has incorporated data from national surveys (National Health and Nutrition Examination Survey), cohort studies (Chronic Renal Insufficiency Cohort Study and CKD in Children Prospective Cohort Study), and EHRs, such as those used within the Veterans Affairs Health System. To further expand this effort, large health care systems could periodically share deidentified or aggregate CKD data with national surveillance programs. These health care systems could be certified to automate submission of these data and be publicly recognized for their efforts. The main challenge encountered in establishing the CDC's CKD Surveillance System has been the difficulty in obtaining data from health care organizations.

Emerging Standards for Accessing EHR Data Should Be Encouraged to Facilitate CKD Research

Most CKD management guideline recommendations are on the basis of expert opinion because of a paucity of high-quality clinical evidence resulting from several factors: (1) few clinical trials in kidney disease, (2) rarity of many kidney diseases (*e.g.*, GN), (3) entrenched expert opinion, resulting in a perceived lack of equipoise and resistance to additional study, and (4) exclusion of patients with CKD from trials in other fields, such as cardiology and oncology. Modern, flexible technologies could use CKD-related EHR data to improve clinical trial design and implementation, including identification and recruitment of study participants with CKD (41,42).

CKD-related EHR data could also facilitate observational, comparative effectiveness, and safety studies of diagnostic and therapeutic approaches to kidney diseases (43–46). Large aggregated datasets could be used to evaluate differences in risk-adjusted clinical outcomes and costs between providers and health systems as well as potentially identify processes that may account for these differences. These clinical datasets could be further enhanced by linking to important clinical outcomes, such as ESRD through the USRDS, renal transplantation through the Scientific Registry of Transplant Recipients, and all-cause mortality through state death files and the National Death Index. Such an approach has been successfully used by the Cardiovascular Research Network, the Food and Drug Administration's Sentinel Initiative, and the Observational Health Data Sciences and Informatics Program (47–50). Realizing the potential of these complex, large, disparate

datasets will require standardization of EHR elements; use of standard codes to identify comorbidities, medications, and other variables; and multidisciplinary expertise in informatics, study design, data management, and statistics. Such efforts could benefit from ongoing collaborations, such as the National Patient-Centered Clinical Research Network and the National Institutes of Health Collaboratory Distributed Research Network (51,52).

Conclusions

CKD is common and associated with significant morbidity and mortality. The care of patients with CKD is complex and data-intensive. The implementation of EHRs by hospitals, large provider organizations, and practice groups presents an opportunity to improve the care of patients with CKD through appropriate incorporation of CKD-related data. However, to optimize care of patients with CKD, it is critical that EHRs be designed to make this information readily accessible. At the individual patient level, CKD care could be improved by using patient- and provider-facing flow sheets; at the population level, aggregated data could facilitate population quality improvement efforts. Such functionality will enable providers and organizations to better manage individual patients and identify groups of patients with CKD for targeted interventions. Methods and standards for extracting, analyzing, linking with external resources, and aggregating EHR data should be developed to enable quality measurement and reporting, CKD surveillance, and research, which are vital to improving outcomes for patients with CKD. Detailed solutions for each of the broad goals outlined in this paper will require collaborative engagement from the community, including primary care providers, nephrologists, and experts in public health, outcomes research, and bioinformatics. To that end, the National Institute of Diabetes and Digestive and Kidney Diseases will convene stakeholders in CKD health information technology, population health management, and research in the fall of 2015 to begin to identify specific solutions for the recommendations included in this manuscript.

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