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Validation of CKD and Related Conditions in Existing Datasets: A Systematic Review

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Abstract

Background—Accurate classification of individuals with kidney disease is vital to research and public health efforts aimed at improving health outcomes. Our objective was to identify and synthesize published literature evaluating the accuracy of existing data sources related to kidney disease.

Study design—A systematic review of studies seeking to validate the accuracy of the underlying data relevant to kidney disease.

Setting & Population—U.S.-based and international studies covering a wide range of both outpatient and inpatient study populations.

Selection Criteria for Studies—Any English-language study investigating the prevalence or etiology of kidney disease, the existence of co-morbid conditions, or the cause of death in those with CKD. All definitions and stages of CKD, including end-stage renal disease (ESRD), were accepted.

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Index Tests—Presence of a kidney disease-related variable in existing datasets, including administrative datasets and disease registries.

Reference Tests—Presence of a kidney disease-related variable defined by laboratory criteria or medical record review.

Results—Thirty studies were identified. Most studies investigated the accuracy of kidney disease reporting, comparing coded renal disease to that defined by estimated glomerular filtration rate (eGFR). Sensitivity of coded renal disease varied widely (0.08–0.83). Specificity was higher, with all studies reporting values of ≥ 0.90 . The studies evaluating the etiology of CKD, comorbidities, and the cause of death in CKD all used ESRD or transplant populations exclusively, and accuracy was highly variable when compared to ESRD registry data.

Limitations—Only English-language studies were evaluated.

Conclusions—Given the heterogeneous results of validation studies, a variety of attributes of existing data sources, including the accuracy of individual data items within these sources, should be carefully considered prior to use in research, quality improvement and public health efforts.

Data validation is fundamental to effective clinical research. Without accounting for underlying assumptions and algorithms used in measurement, systematic error can be introduced into generated data. With the increasing emphasis on research using secondary data sources – the U.S. government’s augmented support of comparative effectiveness research performed with existing data sources, for example – validating the accuracy of underlying information acquires great importance.^{1, 2} Data items particularly prone to error are those related to diseases that are under-reported or variable in definition.

Chronic kidney disease (CKD) is common, morbid, and a growing area of focus in clinical research.^{3–5} Low awareness of CKD, in the public and among providers, is a well-recognized public health concern.^{6, 7} Only recently have commercial and hospital-based laboratories begun to report estimated glomerular filtration rate (eGFR), a measure currently integral to the classification of CKD.^{8, 9} Some medical professionals may not routinely screen for CKD, even in high-risk patients.^{10–12} In addition, translation of medical charts to administrative datasets may not be perfect.¹³ Traditional tools for identifying disease in large databases (such as *International Classification of Disease* (ICD) codes) may therefore poorly reflect the true extent of disease.

Misclassifying CKD can lead to multiple problems. For individual patients, failure to make a timely diagnosis delays delivery of effective treatment.¹⁴ In research efforts, misclassification can bias results. Clearly, the development of surveillance programs to track prevalence of CKD would be hindered by inaccurate diagnosis or coding of CKD. In outcomes research and quality improvement, such inaccuracies could affect the generalizability of results. Missed cases may share characteristics, such as older age or female sex, that influence the observed mix of patients, and thus case-associated characteristics and outcomes may not be representative of the group as a whole. Therefore, before we can have confidence in results, verification of data accuracy is essential.

Our objective was to summarize and interpret studies that sought to validate the accuracy of existing data drawn from different settings as it relates to kidney disease. Cognizant of recent calls for secondary data analysis and comparative effectiveness research, we were particularly interested in large datasets that contained information on the presence, etiology, and associated comorbid conditions of kidney disease, as well as the cause of death in patients with kidney disease. Here, we present a systematic review of studies that address the validity of these kidney disease-related data items in healthcare data.

Methods

Study Design

We performed a systematic review of the literature to identify, review, and summarize peer-reviewed studies that address the accuracy of reported or calculated kidney disease prevalence, cause of CKD, or information on co-morbidities and mortality. All stages of CKD were included, as well as relevant studies examining acute kidney injury and kidney transplant. All human, full-text studies published in English were considered. Studies that compared kidney disease identifiers to the same, re-abstracted identifier (e.g., a comparison of ICD-9-CM codes to re-abstracted ICD-9-CM codes) were excluded.

Identification of the Literature

With guidance from an information specialist, we developed an initial search strategy based on MEDLINE Medical Subject Headings (MeSH) commonly used in a few previously identified relevant studies. Because there is no single MeSH term for CKD, we linked the initial search strategy to a combination of free text key words and additional MeSH terms indicating kidney disease by Boolean operators. We tailored the search to the PubMed electronic database, using limits of Humans and English Language. The full search strategy can be found in Item S1 (provided as online supplementary material available with this article at www.ajkd.org). In addition, we reviewed the references of all included articles. Finally, using the Web of Science's citation manager, we reviewed titles of studies citing any previously identified included article.

Extraction of the Data

Once a study was identified as meeting inclusion criteria, two review authors (MEG, LCP) independently abstracted data items and entered them into predesigned templates. Data extracted included characteristics of the study population and the origin of the datasets used. Information on kidney disease included type (stage 1–5 CKD, ESRD, acute kidney injury (AKI) or kidney transplant) and the method of determination, as well as its gold standard. Prevalence of each variable, if reported, was abstracted. We also noted any reported measure of accuracy, such as sensitivity and specificity, agreement between sources, or kappa statistics, and any subgroup analysis designed to determine which patients were misclassified. We manually calculated unreported sensitivity and specificity if the study supplied the necessary underlying information.

Synthesis of the Data

From the abstracted data, we reported the range of sensitivities and specificities for each variable of interest: presence of kidney disease, cause of kidney disease, comorbid conditions with kidney disease, and cause of death in kidney disease. We produced evidence tables for each variable of interest, including both U.S.-based and international studies.

Results

The flow chart of study selection is displayed in Figure 1. Our PubMed search resulted in 6705 titles, from which we identified 20 articles meeting inclusion criteria. Eight additional studies were identified through references of these identified studies, and two additional studies were identified through the Web of Science citation manager. Characteristics of the final 30 studies (18 of which were US-based) are shown in Table 1. Initial inter-reviewer agreement for abstracted data items was 86%; after clarification and resolution of errors, agreement was 100%.

Accuracy of Reported Presence of Kidney Disease

Ten U.S. studies evaluated the accuracy of the variable “kidney disease” within their data source (Table 2).^{10, 15–23} Six evaluated the accuracy of reported presence of CKD^{10, 15, 16, 19, 21, 22}; four evaluated AKI.^{17, 18, 20, 23} Data sources included Medicare claims data, the National Hospital Discharge Survey data, medical records, laboratory requisition data, a heart failure registry, and hospital administrative databases. Study populations varied widely: healthy outpatients, veterans with diabetes, elderly Medicare beneficiaries hospitalized for acute myocardial infarction, and inpatient hospitalizations, both in general and for specific causes, such as heart failure, COPD, or diabetes. As such, the prevalence of “kidney disease” varied, from 28% to 67% for CKD, and from 1% to 12% in the AKI studies. All but two^{21, 22} defined “kidney disease” by ICD codes in the data source (underlying coding algorithms are listed in Table S1). The gold standard was uniform in the CKD studies; CKD was defined as an estimated glomerular filtration rate (eGFR) of less than 60 ml/min/1.73 m² based on serum creatinine, although Ferris et al.¹⁵ included only Stages 3–4. The AKI studies used a gold standard of medical record mention, a 100% increase in inpatient serum creatinine from nadir to peak, or a graded definition depending on baseline serum creatinine proposed by Hou et al.²⁴ Using these definitions, sensitivity of ranged from 0.11 to 0.45. Specificity was higher, ranging between 0.93 and 1.00.

Eleven international studies also met inclusion criteria (Table 2).^{25, 26, 28–31, 33–37} Seven were Canadian studies;^{25, 26, 28–31, 33} four of the seven had common authorship.^{29–31, 33} All but one²⁶ evaluated code-defined “kidney disease” in administrative databases against medical record mention of CKD. Study populations included patients hospitalized for acute myocardial infarction, patients undergoing percutaneous coronary intervention, admissions for heart failure, and selected hospital discharges. Prevalence of kidney disease was lower than the U.S. studies, ranging from 1.5 to 14.1%. Sensitivity ranged from 0.42 to 0.83. Specificity, when reported, exceeded 0.96 in all studies. The UK³⁵ and Italian³⁷ studies were similar, comparing general practice medical charts to a gold standard of eGFR. Prevalence of CKD ranged from 4.5% in the UK study (with the denominator as the entire study population, some of whom did not have measured serum creatinine) to 9.3% in the Italian study. Sensitivity was low, at 0.08 and 0.15 in the UK and Italian studies, respectively. The Israeli study³⁴ evaluated heart failure registry data, comparing the coded presence of “renal insufficiency” from a mandated admission checklist to an eGFR gold standard. Here, the prevalence was higher, at 56.5%, and the corresponding sensitivity was 0.59. Finally, the Australian study³⁶ estimated the accuracy of yearly incident and prevalent cases of ESRD, comparing ICD-coded administrative data to national registry data. Over the 8-year study period, the authors found an annual average variation between the two systems of 7% in both incident and prevalent cases.

Overall, sensitivity estimates varied by gold standard. Using the most inclusive definition of kidney disease (i.e., the reported algorithm with the highest estimate of sensitivity), we compared sensitivities among studies using the medical record as the gold standard to those using eGFR or, in the AKI studies, a creatinine-based criteria (Figure 2). Studies comparing coded renal disease to laboratory-defined kidney disease reported, on average, lower estimates of sensitivities than those using a medical record comparison ($p < 0.001$). Of note, six of the seven studies using the medical record as a gold standard were international.^{25, 28–31, 33}

Five studies analyzed misclassified cases.^{10, 15, 18, 19, 34} Ferris et al.¹⁵ found that women, whites, and those with less severe CKD were more likely to go unlabeled by ICD-codes; diabetes and hypertension were associated with correct classification. Amsalem et al.³⁴ found that women, older adults, and those with less severe kidney impairment were more likely to be misclassified. Stevens et al.¹⁰ estimated higher sensitivity in severe CKD, but no

difference in sensitivity or specificity by presence of CKD risk factors. Waikar et al.¹⁸ observed higher rates of kidney disease identification in men, older adults, patients hospitalized on a medical service, and those requiring dialysis or dying as an inpatient. Finally, Winkelmayer et al.¹⁹ found increased CKD identification in patients with more physician visits, more hospitalized days, or a previous nursing home stay.

Accuracy of Reported Etiology of Kidney Disease

Three studies reported the accuracy of “etiology of kidney disease”^{38–40}; all evaluated a U.S. ESRD or transplant population (Table 3). The data sources included the Health Care Financing Administration Program Medical and Management Information System (HCFA PMMIS) database (precursor to Center for Medicare and Medicaid Studies or CMS), the United States Renal Data System (USRDS), the New York Statewide Planning and Research Cooperative System (SPARCS) database, the Michigan Kidney Registry (MKR), and data collected from individual dialysis units and transplant centers. The populations were similar: New York Medicare ESRD patients with a hospitalization over a 5-year period, Michigan Medicare ESRD patients, and a national random sample of Medicare ESRD patients. Agreement between data sources on disease etiology ranged between 59% and 89%, or from 79% and 89% if secondary codes were used.

Two studies reviewed misclassified cases. Byrne et al.³⁸ observed a higher match rate in blacks, younger patients, and those with more hospital admissions, and a lower rate in patients with polycystic kidney disease. The USRDS study⁴⁰ showed lowest match rates for patients whose etiology of disease was classified as “other.”

Accuracy of Reported Comorbid Conditions in Patients with Kidney Disease

Three studies estimated accuracy of reported comorbid conditions in patients with kidney disease (Table 4).^{41–43} Longenecker et al.⁴¹ and Merkin et al.⁴² identified a range of conditions in an ESRD population, and Lentine et al.⁴³ evaluated cardiovascular disease in kidney transplant recipients. Data sources include the CMS Medical Evidence Form (a.k.a. Form 2728), data from a national prospective cohort of incident dialysis patients, Medicare billing claims, and a single center kidney transplant administrative database. Two study populations were examined in the three studies: kidney transplant recipients with Medicare as their primary insurance,⁴³ and a national prospective cohort of incident dialysis patients.^{41, 42} In the ESRD populations,^{41, 42} prevalence of comorbid conditions varied, from 10% for cancer to 96% for hypertension. Compared to the medical record, sensitivity estimates for Form 2728 were lower for pulmonary disorders (COPD, 33%) and higher for diabetes (75%) and hypertension (77%).⁴¹ Specificity was high (91% to 100%).

Accuracy of Reported Cause of Death in Patients with Kidney Disease

Two U.S. studies addressed the accuracy of the variable “cause of death” in ESRD populations (Table 5).^{44, 45} Perneger et al.⁴⁴ compared death certificate reports to the Maryland ESRD registry, finding an overall agreement of 31% between sources, with a kappa of 0.24. Rocco et al.⁴⁵ compared the adjudicated classification of death from a national prospective randomized controlled trial of prevalent hemodialysis patients with the HCFA death notification form. Notably, the HCFA death notification form helped to inform the cause of death classification by committee. Agreement varied considerably by cause of death; no overall agreement was calculated.

An Australian study compared “cause of death” from registry data to the death codes to death certificate data (Table 5).⁴⁶ Kappa ranged from 0.01 to 0.73, depending on cause of death. As in the U.S.-based studies, agreement was highest in death from neoplasm.

Indigenous patients were less likely to match. There was no clear temporal change in accuracy overall.

Discussion

This review is, to our knowledge, the first to systematically summarize studies that assess the validity of existing data related to kidney disease. Our results show large variability in accuracy of data items, depending on variable of interest, study population, and, importantly, the comparison gold standard. These results have important implications for clinicians, researchers, provider organizations and payers who seek to improve the health of kidney disease patients through analyses of secondary data sources.

Validation of the variable “kidney disease” is essential in CKD research, as many analyses are predicated on the correct diagnosis and coding of disease. In the 21 studies that address the presence of kidney disease, specificity is high, regardless of gold standard, indicating relatively few false positives. In a study population with a high prevalence of CKD, therefore, a researcher using one of the study datasets could be confident that few patients described as having kidney disease were misclassified. However, if one wanted to assemble a cohort of CKD patients, caution and scrutiny are advisable. Sensitivity of the studies varied widely. Studies using a gold standard of medical record documentation reported higher sensitivities than those using eGFR. No studies incorporated an assessment of kidney function using repeated measurements, proteinuria or *measured* GFR, the latter arguably the best gold standard.

Gold standard choice affects the case population. Defining CKD by medical record likely underestimates the number of cases due to lack of physician recognition or documentation. Using eGFR as a gold standard may overestimate CKD cases by misclassifying normal elderly or people with AKI; further, not all patients may have measured serum creatinine, and eGFR calculated from non-standardized creatinine measurements may be inaccurate.⁴⁷ As an example, despite similar study populations, 67% of Winkelmayer’s¹⁹ population had CKD (defined by eGFR) whereas So et al.³³ found only 17% with either AKI or CKD (defined by medical record). This discrepancy may introduce bias in certain studies. For instance, if white patients with less severe CKD are systematically misclassified as without kidney disease, a comparative effectiveness study of therapeutic interventions may not be generalizable to such patients.

Studies with the same gold standard were also variable. For example, So et al.,³³ Ferris et al.,¹⁵ and Quan et al.²⁹ all evaluated ICD-coded kidney disease against the medical record, estimating sensitivities of 0.83, 0.50, and 0.42, respectively. Many reasons may underlie this variability. Geographic variation in coding practices is well described.¹⁹ Practices may differ between inpatient and outpatient settings. Coding may change over time to incorporate new reimbursement practices, alterations in the numbers of allowable billing codes, and updates in the disease codes themselves.¹⁷ For example, new CKD codes were recently introduced. Using data which differ by medical center, time, or coding practices may systematically bias results.

Validation of CKD-related variables such as etiology, associated comorbid conditions, and cause of death is inherently difficult. First, defining gold standards for variables can be subjective. Tissue diagnosis is considered the gold standard for most etiologies of CKD. However, some patients present too late in the course of disease for an informative biopsy, and biopsy is not often done for certain types of patients, such as those with longstanding diabetes or hypertension. Second, cause of death or kidney disease, if known, is often multifactorial and may not be reducible to one or two ICD codes. For instance, in a patient

with multiple comorbidities, clinical differentiation between diabetes and hypertension as the cause of CKD is difficult. Third, many databases use the same sources of information, such as the Medical Evidence Report (Form 2728). Constructing a gold standard on a common source introduces incorporation bias, and overestimates the accuracy of the underlying data.

Despite these limitations, some interesting patterns emerge in the validation of CKD-related data. Among studies evaluating the cause of kidney failure, less agreement was found in polycystic kidney disease, perhaps because fewer PKD patients are hospitalized for complications of PKD, as compared to, for instance, diabetics with diabetic nephropathy. Using inpatient claims data for analysis of a CKD cohort, therefore, may not only under-capture CKD patients, but may also skew the cause of disease toward the etiologies more commonly hospitalized for non-renal reasons, such as diabetes and hypertension.

In conclusion, this review shows that existing data sources need careful scrutiny before use in any research effort, particularly surveillance studies, outcomes research, quality improvement research and comparative effectiveness research. There is a wide range in accuracy of kidney disease-related variables, and additional research is required to investigate the sources of this variation. In addition, initiatives to improve the quality of underlying kidney disease data should be undertaken, including standardized reporting for prevalence estimates. In particular, efforts must be made to increase providers' recognition and documentation of disease, such as through more systematic testing and standardized ICD coding. Finally, an electronic medical record, integrated with laboratory and vital statistic data, would greatly facilitate clinical and epidemiologic research.

Supplementary Material

Refer to Web version on PubMed Central for supplementary material.

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Figure 1.
Flow Chart of Study Selection

Figure 2.
Estimates of Sensitivity in Studies Evaluating the Presence of Kidney Disease, by Gold Standard. Abbreviation: eGFR, estimated glomerular filtration rate.

Table 1

Characteristics of studies validating the accuracy of existing data sources for examining kidney disease

Type of Study	No.
All studies	30
U.S. studies	18
Non-U.S. studies	12
Accuracy of presence of kidney disease	21
Accuracy of etiology of kidney disease	3
Accuracy of comorbid conditions	3
Accuracy of cause of death	3

Table 2
Characteristics of Studies Addressing the Accuracy of a Presence of Kidney Disease Variable, by Country and Type of Kidney Disease

First Author (Publication Y)	Clinical population	Date of study	N	Kidney disease stage	Identification of kidney disease	Types of kidney disease identified*	Gold standard definition	Prevalence (based on gold standard)	Sensitivity & Specificity
U.S.-Based									
Ferris ('09) ¹⁵	Inpts at UNC Hospital System hospitals	'00-'05	9772	CKD 3–4	ICD-9 codes in hospital accounting system	CKD-related codes	eGFR = 15–60 from two SCRs, 6 mo apart	30.7	28 & 96
Heywood ('07) ²²	Inpt hospitalizations for HF in 285 U.S. hospitals	'01-'04	118,465	CKD 3–5	Registry db flag, extracted from medical record	"Renal insufficiency"	eGFR < 60 on 1st admission SCR	63.6	45 & 95
Kern ('06) ¹⁶	DM pts in VA system (both inpt & outpt visits)	'99-'00	263,730	CKD 3–5, no ESRD	ICD-9 codes in Medicare or VA billing data	1: CKD 2: #1 + CKD pathophysiology 3: #1–2 + DN 4: #1–3 + AKI 5: #1–4 + CKD from systemic disease 6: #1–5 + upper urinary tract cancer 7: #1–6 + anatomic abnormality	eGFR < 60 on index SCR	31.6	1: 20 & 99 2: 35 & 98 3: 39 & 96 4: 40 & 95 5: 41 & 95 6: 42 & 93 7: 42 & 93
Ryan ('07) ²¹	Outpts > 18 y w/ ≥ 2 SCRs, 3 mo apart, in a U Rochester lab	'03-'04	24,492	CKD 3–5	Medical record review of visits from '03-'05	Any chart mention of CKD (102 charts of eGFR-specified CKD only)	eGFR < 60 on two outpt SCRs ≥ 3 mo apart	28.2	27 & NA (based on 102 CKD cases)
Stevens ('05) ¹⁰	Lab clientele > 40 y at Ohio regional lab	'02-'03	53,601	CKD 3–5, no ESRD	ICD-9 codes in lab requisition data	AKI, CKD, or Tx-related codes	eGFR < 60 or < 30 on 1st SCR	30.0	11 & 98 (eGFR < 60); 39 & 96 (eGFR < 30)

First Author (Publication Y)	Clinical population	Date of study	N	Kidney disease stage	Identification of kidney disease	Types of kidney disease identified*	Gold standard definition	Prevalence (based on gold standard)	Sensitivity & Specificity
Winkelmayer (‘05) ¹⁹	Pennsylvania Medicare beneficiaries hospitalized for AMI	‘99- ‘00	1,852	CKD 3– 5, no ESRD/ Tx	ICD-9 codes in Medicare part A or B claims data	Codes in previous 6 or 12-mo: 1: DN 2: AKI 3: HTN-N 4: CKD 5: Misc 6: #1,3,4 7: #1–4 8: #1,3–5 9: #1–5	eGFR < 60 on admission SCr	67.2	6 mo; 12 mo: 1: 2 & 99; 3 & 99 2: 4 & 100; 5 & 100 3: 5 & 100; 7 & 99 4: 9 & 100; 12 & 99 5: 13 & 98; 18 & 96 6: 13 & 98; 16 & 98 7: 14 & 98; 17 & 98 8: 20 & 96; 26 & 93 9: 21 & 96; 27 & 93
Geraci (‘97) ²³	Male veterans surviving hospitalization for an exacerbation of CHF, COPD, or DM at 9 V/A hospitals	‘87- ‘89	1,837	AKI	ICD-9 codes in administrativ e db	AKI-related codes	Medical record mention of AKI developing during hospitalization	1.0	28 & 100
Liagos (‘06) ²⁰	pts discharged from a tertiary hospital in Boston	‘01	13,237	AKI, no ESRD	ICD-9-CM codes in NHDS	AKI-related codes	Hou definition ²⁴ based on nadir & peak SCr during admission	12.0	19 & 100
Waikar (‘06) ¹⁷	Admissions at two Boston teaching hospitals in ‘02 and one hospital in ‘94	‘94 & ‘02	‘94: 7,545; ‘02: 19,206	AKI, no ESRD	ICD-9 codes in hospital administrativ e db	AKI only	100% ↑ in SCr (nadir to peak) during hospitalization	-	‘94: 17 & 99 ‘02: 29 & 97
Waikar (‘06) ¹⁸	Discharges at three Boston teaching hospitals	‘04	97,705	AKI, no ESRD	ICD-9 codes in hospital administrativ e db	1: AKI (total population) 2: AKI requiring dialysis (300 discharges only)	1: 100% ↑ in SCr (nadir to peak); Hou definition ²⁴ 2: Medical record mention of dialysis	5.8 (100% ↑); 12.0 (Hou)	1: 35 & 98 (100% ↑); 28 & 99 (Hou) 2: 90 & 94
International									

First Author (Publication Y)	Clinical population	Date of study	N	Kidney disease stage	Identification of kidney disease	Types of kidney disease identified*	Gold standard definition	Prevalence (based on gold standard)	Sensitivity & Specificity
Humphries ('00) ²⁵	pts who underwent PCI at a single hospital in Vancouver	'94-'95	817	CKD, w/ ESRD	ICD-9 codes in hospitalization db	CKD-related codes	Medical record mention of CKD or dialysis	1.5	82 & 100
Lee ('05) ²⁶	Admissions for HF in 14 hospitals in Ontario	'97-'99	1,592	CKD	ICD-9 codes in administrative data records	CKD-related codes developed by Deyo ²⁷ : 1: during index admission 2: 1 y prior	Initial SCR ≥ 2 mg/dL	14.1	1: 45 & 97 2: 50 & 97
Levy ('99) ²⁸	Adults ≥ 65 y surviving hospitalization w/ MI as primary diagnosis in 6 hospitals in Montreal	'94	224	CKD	ICD-9 codes in discharge db	CKD-related codes	Medical record mention of renal disease	-	77 & NA
Quan ('02) ²⁹	Randomly selected hospital discharge records in Calgary	'96	1,200	CKD	ICD-9 codes in administrative data records	CKD-related codes developed by Deyo ²⁷	Medical record mention of renal disease	3.8	42 & 99
Quan ('08) ³¹	Random sample of hospital discharges from 4 hospitals in Alberta	'03	4,008	CKD	ICD-9 & 10 codes in hospital administrative data	1- CKD-related ICD-9 codes (enhanced Deyo algorithms) ³² 2-CKD-related ICD-10 codes	Medical chart review	4.0	1: 82 & 99 2: 79 & 98
Quan ('04) ³⁰	All inpts discharged from 3 acute care hospitals in Alberta	'96-'97	1,200	AKI	ICD-9 codes in administrative db	AKI-related codes	Medical chart review	3.8	60 & NA ($\kappa=0.63$)
So ('06) ³³	pts hospitalized for AMI in Alberta	'03	193	CKD & AKI	ICD-9 & 10 codes in hospital administrative data	1: CKD-related ICD-9 codes 2: CKD-related ICD-10 codes 3: AKI-related ICD-9 codes 4: AKI-related ICD-10 codes	Medical record mention of CKD or AKI	CKD: 9.3 AKI: 7.8	1: 83 & 96 2: 72 & 98 3: 80 & 98 4: 80 & 96

First Author (Publication Y)	Clinical population	Date of study	N	Kidney disease stage	Identification of kidney disease	Types of kidney disease identified*	Gold standard definition	Prevalence (based on gold standard)	Sensitivity & Specificity
Ansalem (‘08) ³⁴	pts admitted w/ HF to a public hospital in Israel	‘03	3,793	CKD & AKI	Physician- indicated diagnosis from registry data	“Renal insufficiency, either acute or chronic”	eGFR < 60 on 1st admission SCr	56.5	59 & NA
Anandarájah (‘05) ³⁵	General practice pts in UK	‘04	10,975	CKD 3– 5	Medical record review of an electronic GP db	Known to the renal services or diagnosed w/ primary renal disease	eGFR < 60 on SCr	4.5**	8 & NA
Brameld (‘99) ³⁶	ESRD or Tx pts > 25 y receiving CAPD or HD in Australia	‘86- ‘94	782	ESRD	ICD-9 codes in linked administrativ e data	ESRD-related codes	Tx registry–reported incidence & prevalence	-	NA (% variation in both incident & prevalent cases = 7)
Minutolo (‘08) ³⁷	General practice pts in Italy	‘03	77,630	CKD 3– 5	ICD-9 codes in GP administrativ e db	CKD- or AKI-related codes	eGFR < 60 on average SCr	16.2	15 & 100

Note: eGFR is given in mL/min/1.73 m². Conversion units: eGFR in mL/min/1.73 m² to mL/s/1.73 m², x0.01667; SCr in mg/dL to micromole/L, x88.4.

* enumerated if separately analyzed in study

** Prevalence estimate is based on complete sample size, however, only 2771 of the 10975 had creatinine measured

Abbreviations: AKI: acute kidney injury or acute renal failure, AMI, acute myocardial infarction; CAPD: continuous ambulatory peritoneal dialysis, CHF: congestive HF, CKD: chronic kidney disease, COPD: chronic obstructive pulmonary disease; db, database; DM: diabetes mellitus, DN: diabetic nephropathy, eGFR, estimated glomerular filtration rate; ESRD: end-stage renal disease, GP: general practitioner, HD: hemodialysis; HF, heart failure; HTN-N: hypertensive nephropathy, ICD: *International Classification of Diseases*, MI: myocardial infarction, NHDS, National Hospital Discharge Survey; PCI, percutaneous coronary intervention; pt, patient; SCr, serum creatinine; Tx: kidney transplant, UK, United Kingdom; UNC, University of North Carolina; VA: Veteran’s Administration.

Table 3
Characteristics of Studies Addressing the Accuracy of Reported Etiology of Kidney Disease

First Author (Publication Y)	Clinical population	Date of study	No. pts	Stage of kidney disease	Source of etiology data	Source of comparison etiology data	Agreement
Byrne ('91) ³⁸	New York ESRD pts	'82-'87	8,730	5	From HCFA PMMIS	ICD-9 codes from SPARCS data	89%
USRDS Study Group (('92) ³⁹	National ESRD & Tx pts	'87-'88	1692	5, also Tx	From USRDS database	Data obtained from HD units & Tx centers	60%; 79% when including secondary causes
USRDS Study Group (('92) ⁴⁰	Michigan ESRD pts	'77-'87	10,858	5	From USRDS database	From Michigan Kidney Registry	89%

Abbreviations: ESRD: end-stage renal disease, HD: hemodialysis, HCFA PMMIS: Health Care Financing Administration Program Medical and Management Information System, ICD: *International Classification of Diseases*, SPARCS: Statewide Planning and Research Cooperative System, Tx, transplant; USRDS: United States Renal Data System.

Table 4
Characteristics of Studies Addressing the Accuracy of Reported Comorbid Conditions with Kidney Disease

First Author (Publication Y)	Clinical population	Date of study	No. pts	# of co-morbid conditions identified	Source of co- morbid condition	Gold standard source of co- morbid condition	Sample co- morbid disease	Prevalence (%)	Sensitivity & Specificity
Lentine ('09) ⁴³	Pts receiving kidney Tx at a single center w/ Medicare as primary insurer	'91-'02	571	5 diagnoses, 4 procedures ^a	ICD-9 codes from Medicare billing claims, using Part A or B	Tx center data	MI CHF AF CVA VTE CABG	- - - - - -	0.83 & NA 0.93 & NA 0.94 & NA 0.88 & NA 0.83 & NA 1.00 & NA
Longenecker ('00) ⁴¹	National incident dialysis pts	'95-'98	1005	17 ^b	Form 2728	Medical record	CHF MI CVA HTN DM COPD Cancer	44 18 14 95 53 17 10	0.52 & 0.96 0.43 & 0.98 0.47 & 0.99 0.77 & 0.91 0.75 & 0.99 0.33 & 1.00 0.42 & 0.99
Merkin ('07) ⁴²	National incident dialysis pts	'95-'98	965	8 ^c	Patient self- report	Medical record	CHF MI CVA CABG HTN DM COPD Cancer	46 20 16 20 96 54 18 10	0.54 & 0.91 0.60 & 0.93 0.58 & 0.96 0.81 & 0.97 0.81 & 0.76 0.96 & 0.98 0.18 & 0.97 0.69 & 0.97

^aMyocardial infarction (MI), congestive heart failure (CHF), atrial fibrillation (AF), cerebrovascular accident (CVA), venous thromboembolism (VTE), cardiac catheterization, coronary artery bypass grafting (CABG), amputation, peripheral revascularization

^bHIV, hypertension (HTN), diabetes mellitus (DM), insulin use, AIDS, congestive heart failure (CHF), coronary artery disease (CAD), cardiac arrest, cerebrovascular accident (CVA), myocardial infarction (MI), neoplasm, peripheral vascular disease, smoking, chronic obstructive pulmonary disease (COPD), pericarditis, dysrhythmia

^c congestive heart failure (CHF), myocardial infarction (MI), cerebrovascular accident (CVA), coronary artery bypass graft (CABG), hypertension (HTN), diabetes mellitus (DM), chronic obstructive pulmonary disease (COPD), cancer

Table 5
Characteristics of Studies Addressing the Accuracy of Reported Cause of Death in Kidney Disease

First Author (Publication Y)	Clinical population	Date of study	Number of pts	Source of primary cause of death data	Source of comparison cause of death data	Specific causes of death reported	K statistic	Sensitivity, Specificity
Pemeger (‘93) ⁴⁴	Maryland ESRD pts	‘80-‘86	378	USRDS data	Death certificate data	MI Heart disease, other CVA Septicemia Cancer Infection, other Unknown	0.38 0.26 0.18 0.29 0.76 0.19 0.04	- - - - - - -
Rocco (‘02) ⁴⁵	National ESRD pts in randomized trial	‘95-‘99	221	HCFA data	Trial data obtained from medical record & HCFA data	Ischemic heart disease CHF Arrhythmia Other heart disease CVA Cancer Infections Unknown	0.39 0.12 0.38 0.16 0.53 0.95 0.48 0.23	0.38 & 0.95 0.09 & 0.99 0.39 & 0.95 0.86 & 0.79 0.56 & 0.97 0.92 & 1.00 0.47 & 0.97 0.44 & 0.92
Li (‘03) ⁴⁶	Australian ESRD pts	‘97-‘99	1,117	Registry data	Death certificate data	Circulatory Genitourinary Neoplasm Digestive Pulmonary Infection	0.35 0.01 0.73 0.17 0.28 0.11	- - - - - -

Abbreviations: CHF: congestive heart failure, CVA: cerebrovascular accident, ESRD: end-stage renal disease, HCFA: Health Care Financing Administration, MI: myocardial infarction, USRDS: United States Renal Data System.