

Editorial Review

Use of administrative databases for health-care planning in CKD

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Abstract

Good-quality information is required to plan healthcare services for patients with chronic diseases. Such information includes measures of disease burden, current care patterns and gaps in care based on quality-of-care indicators and clinical outcomes. Administrative data have long been used as a source of information for policy decisions related to the management of chronic diseases including cardiovascular disease, diabetes and hypertension. More recently, chronic kidney disease (CKD) has been acknowledged as a significant public health issue. Administrative data, particularly when supplemented by the use of routine laboratory data, have the potential to inform the development of optimal CKD care strategies, generate hypotheses about how to slow disease progression and identify risk factors for adverse outcomes. Available data may allow case identification and assessment of rates and patterns of disease progression, evaluation of risk and complications, including current gaps in care, and an estimation of associated costs. In this article, we use the example of the Alberta Kidney Disease Network to describe how researchers and policy makers can collaborate, using administrative data sources to guide health policy for the care of CKD patients.

Keywords: administrative databases; CKD; health-care planning; policy; AKDN

Introduction

Written records have long been mandatory for the effective planning and quality assurance in any sphere of human endeavor [1–7]. Healthcare systems require reliable information on which to base decisions on care planning and delivery, as well as evaluation of their policy impact [1, 4, 7, 8]. Although some of this information (such as demographic data, burden of disease and risk factors) can be obtained from surveys, disease registries and *ad hoc* studies [1, 8], administrative data can provide details of hospitalizations,

physician encounters and expenditures for hospital stays and treatments [7, 9, 10].

Administrative data can be used to plan health services and to guide policy decisions for the management of people with chronic diseases including cardiovascular disease (CVD), diabetes and hypertension [1, 2, 5, 10]. Recently, chronic kidney disease (CKD) has been recognized as a significant public health issue [11, 12], with over 1 million people on renal replacement therapy (RRT)—with further growth expected to 2.2 million by the year 2030 [11]. Many countries have registries set up to track prevalence, outcomes and care for patients on RRT. However, focusing on the small subset of CKD patients who receive treatment with RRT greatly underestimates the total burden of this condition, given the enormous financial cost associated with the advanced stages of CKD, and the high burden of adverse outcomes of morbidity and mortality even in its earlier stages [11–13].

This paper provides a general overview of administrative health databases and their use in the care of patients with chronic disease including CKD, outlines the potential broad applications of these databases for planning of CKD care and finally describes the Alberta Kidney Disease Network (AKDN) as a specific example of their application in CKD relevant health services research. Finally, the pitfalls and limitations of these databases in research and planning CKD care are discussed.

Administrative databases for healthcare planning in chronic disease: an overview

In general terms, a database is any compilation of information on characteristics and events stored in an organized manner for a specific purpose [3, 5, 6, 14, 15]. Administrative health databases are records of information on individuals registered with healthcare plans or systems [7, 10]. Such information usually includes the characteristics of inpatient and outpatient encounters, physicians' visits, home care visits, prescriptions and stays in

community-based chronic and acute care facilities such as nursing homes and hospices [8, 9].

Administrative health data can be broadly classified as raw data, and derived data obtained via manipulation of the basic data by researchers and analysts. The raw data include specific variables such as patient identifiers, demographics, clinical information on diagnosis, co-morbidities and prescriptions, service utilization, hospital costs and physician billing data [8, 14]. These data are used to derive new variables for more sophisticated analyses and evaluations: for instance, the use of patients' postal code to derive travel distance to care facilities [16, 17], frequency of prescription refills to assess therapy adherence [18] and data on race to determine variation and access to care across ethnic groups [9]. Of note, administrative health databases differ across countries, regions and groups due to varying health policies and socio-economic settings [5–8, 14] (Table 1). For instance, in Canada, information from administrative databases is quite extensive due to a universal healthcare coverage by the government across all provinces and its use for financial reimbursement of physicians

(Table 1). In the USA, variations in information available stem from the different forms of health insurance coverage; for instance, all end-stage renal disease (ESRD) patients (irrespective of their insurance coverage) are captured in the United States Renal Data System (USRDS) database. However, information on hospitalizations, costs and clinical services are restricted to patients covered by Medicare only [6]. In Australia, the UK and other European nations, providing information to the Government is discretionary and therefore limited administrative data may be available [14, 15] (Table 1).

Broad application of administrative databases to health-care planning for patients with chronic diseases

Establishing effective health policy is important for the prevention and management of chronic diseases, regardless of the setting. Policy development requires clear

Table 1. An overview of some administrative databases across regions

Region	Database	Coverage	Information available
North America			
Canada	Provincial Health Authorities Databases:	Provincial	Physicians claims Date, location of service, diagnostic code (ICD-9), provider specialty, cost Inpatient encounters Admission and discharge dates, diagnostic and procedure costs (ICD-9/10), costs, case-mix group Ambulatory care Date, nature and location of service, diagnostic and procedure costs, costs, case-mix group Medication Formulary drugs, prescription date, cost and quantity Registry Date of birth, gender, First Nation status, address
	Alberta		
	British Columbia		
	Manitoba		
	New Brunswick		
	Newfoundland		
	Nova Scotia		
	Ontario		
	Prince Edward Island		
	Quebec		
	Saskatchewan		
USA	Medicare	National: Elderly (age >65 years) The disabled Patients on RRT (USRDS)	Diagnoses, procedure codes, costs, length of stay in hospitals, co-morbidities, outcomes, ambulatory care, prescription, RRT
	Veterans Affairs	American Veterans	As above with exception of RRT
	Medicaid	Individual states for: Low-income individuals and families	As above with exception of RRT
	Kaiser Permanente	Regional and privately funded	Diagnoses, procedure codes, costs, length of stay in hospitals, co-morbidities, outcomes, ambulatory care, prescription, RRT
Europe			
UK	GPRD	National	Demographics, diagnoses, prescriptions, referrals, smoking status, height, weight, immunizations, laboratory results
Finland	Finnish Hospital Discharge Register	National	Diagnoses, procedure codes, costs, length of stay in hospitals, co-morbidities, outcomes
Sweden	Hospital Discharge Register	National	Diagnoses, procedure codes, length of stay in hospitals
Australia	NHMD	National	Diagnoses, procedure codes, costs, length of stay in hospitals, co-morbidities, outcomes

GPRD, General Practice Research Database; ICD, International Classification of Disease; NHMD, National Hospital Morbidity Database; RRT, renal replacement therapy; USRDS, United States Renal Data System.

Table 2. Policy development for CKD care planning

Objective	Required information	Applications in CKD
Setting the policy goal	Magnitude of the problem	Burden of CKD and risk factors Cost and consequences
	Ensuring equity in care	Distribution of CKD care across population demographics (age, social class, geography, race etc.) Disparities in care and outcomes
	Establishing care plans various phases of CKD	Recognition and modification of risk Early CKD care and prevention of progression Late CKD care and minimizing complications Management of patients with ESRD
Measuring policy impact	Assessing changes in quality indicators in CKD care	Improved care delivery Achievement of care targets (quality of care indicators) Changes in attitude, practice and attitude of practitioners and patients Changes in health-care policy
	Assessing changes in clinically relevant outcomes	Rates of incident ESRD Rates of CVD outcomes Improvement in quality of life

CKD, chronic kidney disease; CVD, cardiovascular disease; ESRD, end-stage renal disease.

objectives and a strategy to measure its impact [1, 2]. Data required include measures of disease burden, care distribution, prevention efforts and their workability, outcome measurements and assessment of intervention effectiveness [1, 2, 10] (Table 2 and Figure 1).

Administrative databases (particularly when combined with laboratory data) can inform the development of optimal CKD prevention strategies, generate hypotheses about new ways of slowing disease progression and assess the rate of (and changes in risk for) adverse

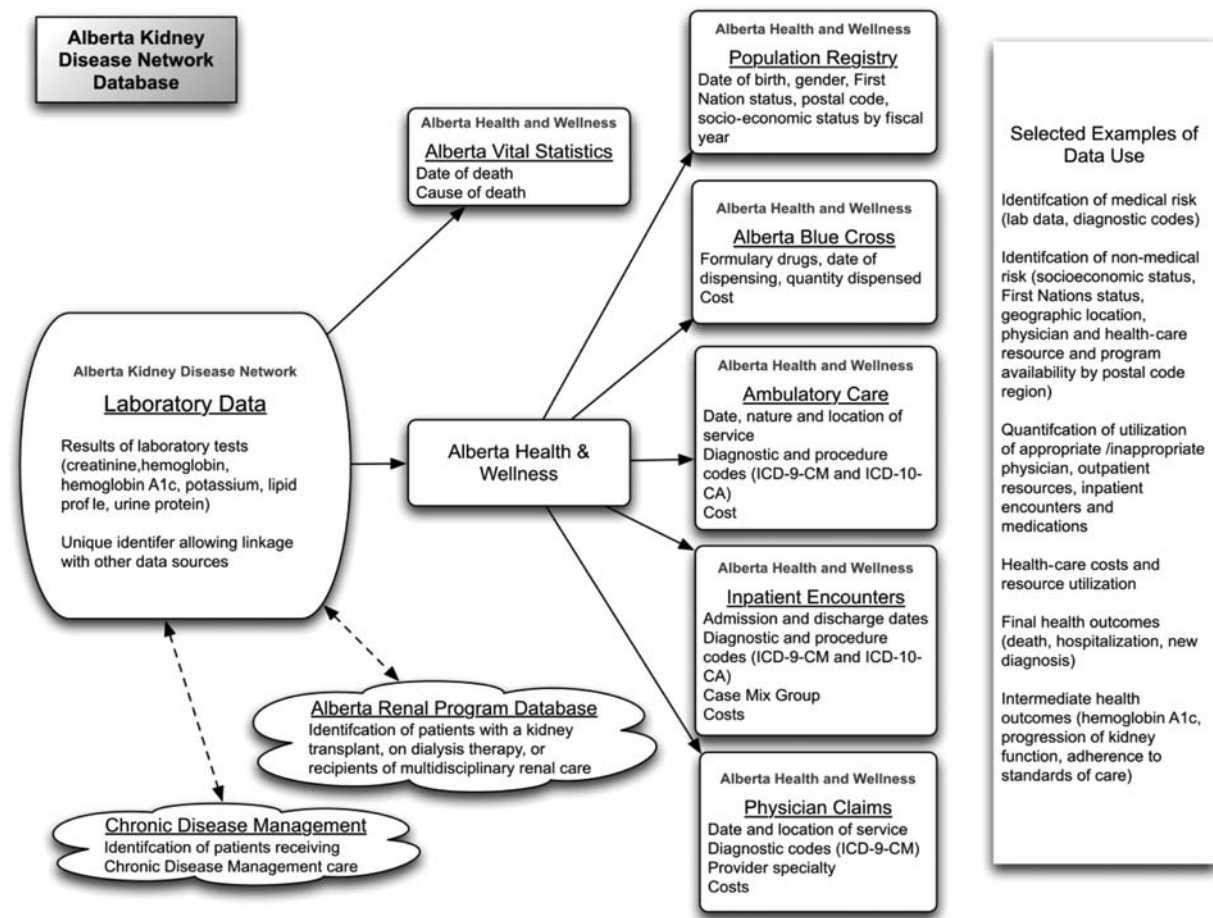


Fig. 1. Data sources and variables linked to the AKDN laboratory data (adapted from Hemmelgam *et al.* [19]). No Permission required in accordance with BioMed Central’s Open Access Charter.

Table 3. Relevant information available in administrative databases to assist healthcare planning in CKD

Objectives	Relevant information available	Applications
Setting the policy goal Assessing the magnitude of the problem	Burden of CKD by population demographics and geography Overall burden in the population Burden in high-risk subgroups, ethnic populations, diabetics, hypertensives etc. Risk identification and risk reduction strategy: Identification of risk factors adverse outcomes Identification of strategies that slow progression of CKD	Development of general or targeted prevention strategies for CKD in the communities Formulation of better care delivery strategies for improved outcomes
Ensuring equity in care delivery	Data on gaps and inequalities in all facets of CKD care in comparison to defined standards by geography and race	Identification of barriers to efficient care delivery, including remoteness (travel distance/time to care centers), and physician availability which impact outcomes Identification of areas for improvement with new approaches to care
Assessing the policy impact	Status of care for people with advanced CKD: Information on quality indicators for patients with ESRD (anemia, bone disease, malnutrition and depression) Access and utilization of RRT: Information on access and utilization of RRT in population subgroups and relevant data on utilization barriers to identify populations with decreased utilization of the various RRT modalities Process evaluation and quality assurance: Studies on evaluation of whether recommended quality care and evidence-based interventions are delivered as intended Surveillance and monitoring: Information on trends in the risk and burden of disease for monitoring and surveillance of CKD across population groups over time Strengthening evidence and provision of higher quality decision data: Strategies that are associated with better outcomes in observational analyses of administrative data can be tested in randomized controlled clinical trials to build better evidence and quality data Comparative effectiveness research, economic evaluations and health technology assessment	This information can be used to guide policy for efficient and equitable RRT provision and delivery This provides information of gaps in care—facilitating strategies to close the gaps and improve outcomes Assess policy impact and direct care focus Guide clinical and policy decisions Cost implications of the various care approaches and implementation can be derived and used to outline optimal cost savings and cost effective care delivery measures

outcomes [12, 19]. Available data may allow assessment of risk evaluation, case identification, rate and pattern of disease progression, complication rate and associated costs—which can all be used to guide policy direction. Administrative data may also allow researchers to measure quality-of-care indicators (e.g. proportion of patients receiving recommended care such as the use of statins, renin-angiotensin inhibition where indicated and/or proportion reaching relevant treatment targets for proteinuria, glycosated hemoglobin etc.) and their impact on clinically relevant outcomes. Such assessment can lead to insight into care delivery gaps, including complication rates, or variations in care such as unusually high (e.g. RRT) or low (e.g. beneficial preventive strategies) rates of health service utilization, with their associated costs (Table 3).

Illustrating the use of administrative data to guide health planning for CKD: the AKDN as a case study

The need for information on how to optimize CKD care led to the development of the AKDN in Alberta, Canada (<http://www.akdn.info/>) [19]. The AKDN is a research

consortium of kidney specialists, cardiologists, health economists, primary care doctors and policy makers with the following specific objectives [19]:

- To determine the prevalence and identify those at high risk for CKD in Alberta, Canada.
- To determine rates of progression of CKD.
- To determine whether access to/quality of specialized medical care and/or rates of progression of kidney disease differs by gender, age, location of residence or ethnic background.
- To determine the healthcare costs of caring for patients with CKD.
- To determine optimal treatments for patients with CKD.

The AKDN repository was obtained by linking laboratory data to administrative and other computerized data sources to allow assessment of socio-demographic characteristics, clinical variables and health outcomes. The AKDN database provides information not only on CKD, but also on other chronic diseases, as it includes data on all patients in Alberta who have had routine laboratory investigations [19] (Figure 1). A unique provincial health number is used to link Alberta Government data with the

Table 4. Specific examples of studies done using AKDN administrative data to address key issues in CKD care

Type of information analyzed from data	Examples of type of data utilization
Defining and assessing magnitude and consequences of CKD Identification of risk, case definition and disease/risk stratification	Ronksley <i>et al.</i> [28] Gao <i>et al.</i> [34] Tonelli <i>et al.</i> [26] Clement <i>et al.</i> Validation of a case definition to define chronic dialysis using outpatient administrative data. <i>BMC Med Res Methodol</i> 2011; 11: 25 Hemmelgarn <i>et al.</i> [13]
Assessing equity and disparities in CKD care and burden of complications Identification of non-medical risk (socio-economic status, First Nations status, geographic location, physician and healthcare resource and program availability by postal code region)	Ayyalasomayajula <i>et al.</i> , A novel technique to optimize facility locations of new nephrology services for remote areas. <i>Clin J Am Soc Nephrol</i> 2011; 6: 2157–2164 Tonelli <i>et al.</i> Association between proximity to the attending nephrologist and mortality among patients receiving hemodialysis. <i>CMAJ</i> 2007; 177: 1039–1044 Gao <i>et al.</i> [21] Chou <i>et al.</i> Quality of care among Aboriginal hemodialysis patients. <i>Clin J Am Soc Nephrol</i> 2006; 1: 58–63 Tonelli <i>et al.</i> Residence location and likelihood of kidney transplantation. <i>CMAJ</i> 2006; 175: 478–482
Quantification of utilization of appropriate/inappropriate physician encounters, hospitalization risk and complications	James <i>et al.</i> CKD and risk of hospitalization and death with pneumonia. <i>Am J Kidney Dis</i> 2009; 54: 24–32 James <i>et al.</i> Risk of bloodstream infection in patients with chronic kidney disease not treated with dialysis. <i>Arch Intern Med</i> 2008; 168: 2333–2339 Rucker <i>et al.</i> [16]
Policy development and impact Healthcare costs and resource utilization	Tonelli <i>et al.</i> Economic implications of screening strategies in arteriovenous fistulae. <i>Kidney Int</i> 2006; 69: 2219–2226 Wiebe <i>et al.</i> [17] Barnieh <i>et al.</i> A description of the costs of living and standard criteria deceased donor kidney transplantation. <i>Am J Transplant</i> 2011 Hemmelgarn <i>et al.</i> [22] Manns <i>et al.</i> Population based screening for chronic kidney disease: cost effectiveness study. <i>BMJ</i> 2010
Final health outcomes (death, hospitalization, new ESRD)	Hemmelgarn <i>et al.</i> [13] Conley <i>et al.</i> Association between GFR, proteinuria, and adverse outcomes among White, Chinese, and South Asian Individuals in Canada. <i>Am J Kidney Dis</i> 2011 Tonelli <i>et al.</i> Higher estimated glomerular filtration rates may be associated with increased risk of adverse outcomes, especially with concomitant proteinuria. <i>Kidney Int</i> 2011 James <i>et al.</i> CKD and risk of hospitalization and death with pneumonia. <i>Am J Kidney Dis</i> 2009; 54: 24–32 Manns <i>et al.</i> Enrolment in primary care networks: impact on outcomes and processes of care for patients with diabetes. <i>CMAJ</i> 2011
Intermediate health outcomes (hemoglobin A1c, progression of kidney function, adherence to standards of care)	Shurraw <i>et al.</i> Association between glycemic control and adverse outcomes in people with diabetes mellitus and CKD. <i>Arch Intern Med</i> 2011; 171: 1920–1927
RCTs	Barnieh <i>et al.</i> Evaluation of an education intervention to increase the pursuit of living kidney donation: a randomized controlled trial. <i>Prog Transplant</i> 2011 Manns <i>et al.</i> A Cluster Randomized Trial of an Enhanced eGFR Laboratory Prompt in Chronic Kidney Disease. <i>CJASN</i> 2012 (in press) Interdisciplinary Chronic Disease Collaboration [1]
KT activities	

CKD, chronic kidney disease; KT, knowledge translation; RCTs, randomized controlled trials.

provincial laboratory database and a number of other data sources such as the provincial renal program databases, and other databases related to program delivery such as the Chronic Disease Management database [19].

The Alberta provincial health ministry (Alberta Health and Wellness; AHW) insures all residents of the province of Alberta through a universally available healthcare plan. All insured residents are included in the AHW database, which include data that allow estimation of the prevalence

of CKD (and its associated complications) when used in conjunction with laboratory data through validated algorithms; determine the adequacy of the current care through examination of quality indicators and assess health-care utilization, service deliverables, health outcomes and costs data; and related socio-demographic data.

The AKDN databases and their potential applications to CKD care are described in detail elsewhere [19]. In brief, the data include basic demographic information to

provide information on the burden of disease and care disparities across various racial and ethnic groups such as Aboriginal, Asian (Chinese and South Asian) ethnicity and also by socio-economic status. The database also contains a six-digit postal code which enables unique geographic information system (GIS) analyses to be performed on access to care and relationships to travel distance/time [19].

Prescription claims data (available for Alberta residents aged 65 and older) permit evaluation of medication utilization, costs and studies to evaluate the association between the use of specific agents or classes and clinical outcomes [19]. Data ranging from ambulatory care encounters, hospitalizations, costs, outcomes including CVD events and RRT utilization are captured for analysis in conjunction with laboratory data for policy-relevant research (Figure 1 and Table 4) [19].

Specific examples of the work by AKDN in the various domains of CKD care are shown in Table 4.

The role of AKDN data in formulating policy for CKD and other chronic diseases

The last decade has witnessed progress in moving research findings outside the academic arena through knowledge translation (KT) strategies [1, 2]. These KT activities target end-users such as the care providers, advocacy groups, healthcare administrators, policy-makers and patients—ensuring that research findings are used to improve the care of CKD patients in Alberta and elsewhere [1, 20–22].

The AKDN uses an integrated KT strategy in all phases of research—including question generation, study design and conduct, as well as implementation of the tested interventions [1]. In addition, stakeholders such as practitioners, patients and policy makers are involved in AKDN research activities to ensure that the knowledge generated is used to optimize the care of patients with CKD in our communities [1].

Strengths and limitations of administrative data for policy-relevant CKD research

Administrative databases have some advantages over data obtained from primary surveys or studies [3–10, 14, 23]. Generally, administrative data have a wider population coverage with longer follow-up periods than what is possible in primary studies (e.g. Medicare provides data on over 96% of the elderly and all patients on RRT in the USA; AKDN contains data on over 3 million Albertans with nearly 10 years of follow-up data on measurements and outcomes). Also, administrative data are often more cost effective to obtain than the primarily designed studies or surveys [7, 15, 24].

Despite these key advantages, administrative data have some limitations worthy of mention. First, administrative data are usually not obtained for research purposes [6, 10, 15]. Second, administrative data do not

usually include important clinical data such as blood pressure and lifestyle variables (smoking, exercise and diet) and other important potential characteristics such as patients' satisfaction and psychological impact of care.

Third, the administrative data are limited to records obtained for the purposes of reimbursement (i.e. physician claims and drug benefits), or tracking healthcare service delivery (i.e. hospitalizations or emergency room use) [8, 15, 25]. Information not related to this may be lacking or limited in the healthcare systems where such needs do not exist. For instance, Alberta administrative data contain information on the use of medications only for those aged 65 years and above and those covered under the provincial drug plan. Knowledge gaps associated with these inherent limitations could be addressed using targeted primary surveys and studies. Fourth, limited or complete absence of validation for certain characteristics in some databases, highly variable follow-up and selected (potentially non-generalizable) populations are weaknesses when compared with well-designed population-based cohorts. In addition, heterogeneity in the demographics of population covered and differences in the content of the databases across regions can also limit their applications.

Conclusion

Administrative databases provide opportunities for defining disease burden, adverse outcomes and care gaps—all useful for setting policy goals and improving the quality of care. Given that CKD is primarily defined by serum creatinine and albuminuria, administrative data are particularly informative for the study of CKD when combined with laboratory data. Administrative databases are also good sources for delineating disparities in care across socio-demographic groups—which facilitate strategies aimed at ensuring equity [7, 13, 14, 17, 21, 22, 26–34]. Finally, such databases could be used to measure the impact of applied interventions toward reducing the burden of CKD and its consequences.

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