

A Province-wide Central Repository of Laboratory and Administrative Data to Support CKD Research Alberta Kidney Disease Network

Setting & Background

Lead Organization: The Alberta Kidney Disease Network (AKDN) is a collaborative group of nephrology researchers across Alberta, Canada. The network is led by researchers at the University of Alberta and the University of Calgary.

Key Partners

- Researchers across Alberta
- Alberta Health (AH), Alberta's health ministry
- Alberta Health Services (AHS), the province-wide, fully integrated health system
- Laboratories in Alberta

Health Care System Structure: In Alberta, health care is under the jurisdiction of Alberta Health (AH), the province's health ministry. Services, including hospitalization, physician visits, and associated testing (including laboratory services), are provided by Alberta Health Services (AHS). AHS serves 4 million Albertans. AHS contracts out laboratory services to private companies but laboratory data are maintained within AHS domains.

Target Population: Adult residents of Alberta, with special emphasis on patients with chronic kidney disease (CKD).

Data Sources: AKDN has developed a central repository of laboratory and administrative data for adults within Alberta. Alberta residents receive a unique provincial health number, allowing linkage of laboratory data to several computerized AH administrative data sources (see *Table 1: AKDN Data Sources*).

Time Period: 2002 to present.

Contacts for Additional Details:

Brenda Hemmelgarn, MD, PhD, FRCPC

Brenda.Hemmelgarn@albertahealthservices.ca

Introduction

The AKDN registry combines laboratory and administrative data for all patients in the Canadian province of Alberta. The province-wide project was developed based on success of a citywide pilot project in Calgary. AKDN data are used to conduct epidemiology, cost, health services, and clinical trial research as well as to guide policy development and the delivery of health care.

AKDN's objectives include assessing the state of CKD and CKD risk in Alberta and improving CKD care. Specifically, AKDN aims to:

- Identify patients at high risk for CKD;
- Identify patients with CKD/determine CKD prevalence;
- Determine rates of CKD progression;
- Understand how gender, age, location of residence, or ethnic background influence access to/quality of specialized medical care and/or rates of CKD progression;
- Determine health care costs of caring for patients with CKD; and
- Determine optimal treatments for patients with CKD.

Methods

In 2002, a team of nephrology researchers began an effort to link administrative and laboratory data to identify elderly patients with CKD in Calgary, Alberta. After citywide success in Calgary, the team decided to expand the activity to identify patients across the province of Alberta.

Key steps included:

- Establishing and maintaining the team;
- Acquiring funding;
- Generating partnerships;
- Linking data sources;
- Ensuring database security;
- Establishing protocols for estimating GFR; and
- Sharing data with external researchers.

Establishing and Maintaining the Team

AKDN is led by an executive team of nephrology researchers (Brenda Hemmelgarn, MD, PhD, FRCPC; Braden Manns, MD, MSc, FRCPC; and Marcello Tonelli, MD, SM, FRCPC) at the University of Calgary. The executive team has engaged approximately 10 nephrology researchers from across Alberta. As needed, the executive team has sought out experts in data storage, privacy, and contracts to facilitate the database development.

Ongoing support to maintain the database and oversee research activities is essential.

Necessary Staff

- Data manager (1 FTE) to clean, administer and maintain the data.
- Data analysts (7 FTE) must understand the dataset's nuances—most have a master's degree in health services research—and they also must be adept in using SAS. Some have started as graduate students and stayed with the project.
- Research manager to oversee all research activities.
- Human Resources manager to oversee budget issues.

Core team members meet on a monthly basis and the extended team meets every six months. Given that they are based in Edmonton and Calgary, team members meet via video conference. Bi-weekly seminars are held with all team members to share research findings.

Acquiring Funding

Launching and maintaining the AKDN database requires resources to support salaries for project team members, costs for extracting administrative and laboratory data from AH/AHS and Alberta laboratories, maintenance of the database, and storing/backing-up data on the server. The Northern and Southern Alberta Renal Programs (the two AHS programs responsible for providing care for end-stage renal disease patients across the province) provided initial funding for the project. The Alberta Renal Programs have been strong supporters of the AKDN as they appreciate the benefits of having province-wide CKD data. Maintenance funds for the project are acquired through operating and provincial team grants.

Generating Partnerships

AKDN established partnerships with AH and AHS to facilitate access to laboratory and administrative data for provincial residents. Additionally, collaboration with AHS's Northern and Southern Renal Programs has provided both guidance and financial support to the AKDN team. Though laboratory data are now acquired through AHS—initially they were obtained directly from laboratories—direct relationships with Alberta laboratories were established early in the process. Alberta laboratories helped demonstrate that linking laboratory and administrative data was possible in the initial Calgary-based pilot project. AKDN researchers have continued to collaborate with Alberta laboratories on grant proposals, manuscripts, research efforts, and quality improvement projects. Currently, AKDN is working with the laboratories to link to laboratory data directly from their clinical pathway.

Linking Data Sources

The AKDN has developed a process to retrieve, store and maintain computerized laboratory data and relevant laboratory tests for all patients who obtain specific laboratory measurements in Alberta. AKDN uses a unique patient identifier assigned to each patient to link the laboratory data to administrative data (including demographic, mortality, and claims information) from several AHS programs (see Table 1: AKDN Data Sources). All data are available electronically, so manual data entry is unnecessary.

Table 1: AKDN Data Sources

Dataset	Data	Purpose
Computerized Laboratory Data	<p>Serum Tests:</p> <ul style="list-style-type: none"> • Creatinine • Hemoglobin • Potassium • Hemoglobin A1C • Fasting total cholesterol • Fasting high density lipoprotein • Fasting low density lipoprotein <p>Urine Tests:</p> <ul style="list-style-type: none"> • Urine dipstick • Urine microalbumin-creatinine ratio • Urine protein-creatinine ratio • 24 hour urine protein <p>Data elements:</p> <ul style="list-style-type: none"> • Unique patient identifier • Patient date of birth • Patient gender • Test name • Test result • Test date • Health region • Location of test (in- or out-patient)* 	<p>Identification of patients with CKD</p> <p><i>*Test location differentiates test results obtained during a hospitalization (potentially influenced by an acute illness) from those obtained in the outpatient setting (which may better reflect stable medical conditions)</i></p>
Alberta Vital Statistics	Date of death, cause of death	Assessment of mortality as an outcome
Population Registry	Date of birth, gender, First Nation status, postal code, socioeconomic status by fiscal year	Identification of non-medical risk factors
Alberta Blue Cross	Formulary drugs, date of dispensing, quantity dispensed, cost	Evaluation of drug use and its impact on outcomes
Ambulatory Care	Date, nature and location of service, diagnostic and procedure codes (ICD 9-CM, ICD 10-CA), cost	<p>Determination of disease incidence/prevalence with validated algorithms for common medical conditions, including hypertension (Quan, 2009), diabetes (Hux, 2002), acute myocardial infarction (Austin, 2002), congestive heart failure (Lee, 2005), stroke (Kokotailo, 2005)</p> <p>Identification of dialysis patients (supplemental to Renal Program data)</p>
Inpatient Encounters	Admission and discharge dates, diagnostic and procedure codes (ICD 9-CM, ICD 10-CA), case mix group, costs	
Physician Claims	Date and location of service, diagnostic and procedure codes (ICD 9-CM, ICD 10-CA), providers specialty, costs	
Chronic Disease Management	Date and location of visits	Identification of patients receiving Chronic Disease Management care
Alberta Renal Program Database	CKD clinic visits, initiation of renal replacement therapy including modality and date; receipt of kidney transplant including date	Identification of patients with a kidney transplant, on dialysis therapy, or recipients of multidisciplinary renal care.

Ensuring Database Security

To ensure privacy and security requirements are met, the AKDN set specifications for data storage and access. Contracts with AH and AHS set specific privacy and security standards. AKDN data are stored on a single server—the University of Calgary server—that complies with security standards for individual patient data. The database operates in a Windows system, with limited access via secure personal computers. Patient identifiers are removed from the database prior to use in research. Patient data are kept within the province.

Establishing Protocols for Estimating GFR

AKDN established processes to ensure accurate estimates of kidney function over time. AKDN estimates GFR using the CKD Epi equation. In 2003, to reduce inter-laboratory variation in eGFR creatinine measurements, Alberta laboratories transitioned to creatinine analysis calibrated to the isotope dilution mass spectrometry (IDMS) reference standard. (A laboratory-specific correction factor is applied where necessary to ensure standard creatinine measurements across laboratories.) As a result, AKDN switched from the non-IDMS traceable to the IDMS-traceable CKD pPi equation. To ensure consistency of eGFRs before and after the transition, the linear relationship between non-IDMS- and IDMS-traceable GFR estimating methods were established.

Data on race are not available—GFR is estimated assuming White race. However, less than 1% of the Alberta population is of Black race so little misclassification of eGFR is anticipated.

Rather than using a single creatinine measurement to calculate baseline kidney function, an index eGFR is calculated as the mean of all outpatient serum creatinine measurements taken within a six-month period from the first creatinine measurement. For subjects with more than a single measurement, the index date is set as the latest measurement date within the six-month period. Using an index eGFR calculated as a mean of multiple measurements reduces the affect of regression to the mean, a statistical phenomenon that occurs when repeated measurements with wide variability are made on the same subject.

Sharing Data with External Researchers

To access the database, non-AKDN researchers must submit a one-page proposal that is reviewed by the executive committee. Since data cannot leave the province, all data must be reviewed within the province.

Results

Linkage of laboratory data to administrative and other computerized data sources provides a rich source of information for assessment of socio-demographic characteristics, clinical variables, and health outcomes. The database can be used to generate a variety of unique cohorts to address numerous research questions. While the database was originally developed to support nephrology research, it includes information on all patients who have obtained routine laboratory investigations, not just those with kidney disease. Therefore, AKDN data can be used to generate cohorts of patients with other chronic conditions (e.g., diabetes, hypertension).

The database has been used to gain a more in-depth understanding of CKD at the province level including risk, prevalence, and progression of CKD. AKDN data have been used to address numerous research questions. Key studies include:

- **Assessment of an online, interactive CKD clinical pathway (ICDC, 2014):** AKDN is currently implementing a cluster randomized clinical trial to assess implementation of a CKD clinical pathway designed to improve diagnosis, management, and referral of patients with CKD.
- **Potentially preventable hospitalization as a complication of CKD: a cohort study (Weibe, 2014):** The AKDN database was used to identify a cohort of patients in Alberta with at least one serum creatinine measurement between 2002 and 2009. A retrospective analysis of the cohort showed remote dwelling patients and patients with comorbidities (e.g., heart failure, liver disease) were at highest risk for hospitalization.
- **A cluster randomized trial of an enhanced eGFR prompt in chronic kidney disease (Manns, 2012):** The study found an enhanced laboratory prompt with specific CKD management recommendations did not increase use of renin-angiotensin-aldosterone system inhibitors among elderly CKD patients identified through the AKDN database.
- **Using proteinuria and estimated glomerular filtration rate to classify risk in patients with chronic kidney disease: a cohort study (Tonelli, 2011):** A system for risk stratification based on eGFR and proteinuria was assessed in a cohort of CKD patients identified through the AKDN database. The system was validated against internal (AKDN) and external (non-AKDN) cohorts. Results suggest risk stratification using proteinuria and eGFR may reduce unnecessary referrals for care at the cost of not referring or delaying referral for some patients who go on to develop kidney failure.

[See publications from AKDN.](#)

Barriers & Solutions

- **Meeting confidentiality and privacy requirements.** AHS and AH have specific privacy requirements for accessing individual patient data. To ensure compliance with privacy requirements, AKDN hired a research manager to oversee administrative procedures, ensure data sharing contract requirements are met, and ensure data are maintained appropriately.
- **Ensuring data are accurately represented.** AKDN data have certain limitations (e.g., use of administrative data for comorbidities, data limited to subjects who have sought and received care). AKDN ensures all within-network researchers have appropriate expertise and understanding of data limitations to ensure data are not mis-represented.
- **Engaging primary care providers in research efforts.** Given the diversity of this group, engaging primary care providers in research efforts can be challenging. AKDN involved primary care providers from the start of AKDN, who have helped target primary care physicians. AKDN representatives have also presented the database at primary care conferences.

Facilitators

- **Establishing a core group of dedicated team members with a common vision.** The AKDN executive team championed the project and spearheaded AKDN efforts, including grant writing and staff oversight.
- **Identifying supportive partners who understand the value of the project.** AKDN received significant support from the Alberta Renal Disease Networks, who appreciated the value of generating data relating to CKD risk, prevalence, progression, and care.

Next Steps

Future AKDN Activities

- Expanding intervention trials using cohorts identified through the AKDN database. Acute kidney injury prevention is a primary focus area for future intervention trials.
- Incorporated clinical data (e.g., vital signs) from electronic health records (EHR). AKDN researchers are currently working on linking data from Sunrise Clinical Managers, which houses all in-patient data from Calgary. Alberta is currently exploring options for a province-wide EHR for in- and out-patient data, which may allow linking of EHR data to the AKDN database in the future.
- Current data sources within Alberta do not include patient-reported outcomes and symptoms. Opportunities for assessing patient-reported outcomes and symptoms are being explored at the National level, which may allow these measures to be incorporated within network.

Additional Resources

- Data definitions and the associated SAS code for acute myocardial infarction, congestive heart failure, diabetes, hypertension and stroke-related events are available from the Interdisciplinary Chronic Disease Collaboration (ICDC):
<http://www.icdc.ca/research/definitions-sas-code>

References

AKDN Background

The Alberta Kidney Disease Network (AKDN). <http://www.akdn.info>

The Interdisciplinary Chronic Disease Collaboration (ICDC). <http://www.icdc.ca>

Hemmelgarn BR, Clement F, Braden JM, Klarenbach S, James MT, Ravani P, Pannu N, Ahmed SB, MacRae J, Scott-Douglas N, Jindal K, Quinn R, Culleton BF, Wiebe N, Krause R, Thorlacius L, Tonelli M: Overview of the Alberta Kidney Disease Network. *BMC Nephology*. 2009; 10:30 <http://www.ncbi.nlm.nih.gov/pubmed/19840369>

Select AKDN Studies

Interdisciplinary Chronic Disease Collaboration (ICDC). Assessment of an Online, Interactive CKD Clinical Pathway. 2014. Available from: <http://www.icdc.ca/research/selected-projects#1-online-interactive-ckd-clinical-pathway>

Manns B, Tonelli M, Culleton B, Faris P, McLaughlin K, Chin R, Gooch K, McAlister FA, Taub K, Thorlacius L, Krause R, Kearns M, Hemmelgarn B; Alberta Kidney Disease Network. A cluster randomized trial of an enhanced eGFR prompt in chronic kidney disease. *Clin J Am Soc Nephrol*. 2012 Apr;7(4):565-72. <http://www.ncbi.nlm.nih.gov/pubmed/22344504>

Tonelli M, Muntner P, Lloyd A, Manns BJ, James MT, Klarenbach S, Quinn RR, Wiebe N, Hemmelgarn BR; Alberta Kidney Disease Network. Using proteinuria and estimated glomerular filtration rate to classify risk in patients with chronic kidney disease: a cohort study. *Ann Intern Med*. 2011 Jan 4;154(1):12-21. <http://www.ncbi.nlm.nih.gov/pubmed/21200034>

Wiebe N, Klarenbach SW, Allan GM, Manns BJ, Pelletier R, James MT, Bello A, Hemmelgarn BR, Tonelli M; Alberta Kidney Disease Network. Potentially preventable hospitalization as a complication of CKD: a cohort study. *Am J Kidney Dis*. 2014 Aug;64(2):230-8. <http://www.ncbi.nlm.nih.gov/pubmed/24731738>

Disease Algorithms

Austin PC, Daly PA, Tu JV. A multicenter study of the coding accuracy of hospital discharge administrative data for patients admitted to cardiac care units in Ontario. *Am Heart J*. 2002;144(2):290–296. <http://www.ncbi.nlm.nih.gov/pubmed/12177647>

Hux JE, Ivis F, Flintoft V, Bica A. Diabetes in Ontario: determination of prevalence and incidence using a validated administrative data algorithm. *Diabetes Care*. 2002;25(3):512–516. <http://www.ncbi.nlm.nih.gov/pubmed/11874939>

Kokotailo RA, Hill MD. Coding of stroke and stroke risk factors using international classification of diseases, revisions 9 and 10. *Stroke*. 2005;36(8):1776–1781. <http://www.ncbi.nlm.nih.gov/pubmed/16020772>

Lee DS, Donovan L, Austin PC, Gong Y, Liu PP, Rouleau JL, Tu JV. Comparison of coding of heart failure and comorbidities in administrative and clinical data for use in outcomes research. *Med Care*. 2005;43(2):182–188. <http://www.ncbi.nlm.nih.gov/pubmed/15655432>

Quan HKR, Hemmelgarn B, Tu K, Chen G, Campbell N, Hill MD, Ghali WA, McAlister F. Validation of a case definition to define hypertension using administrative data. Hypertension. 2009. <http://www.ncbi.nlm.nih.gov/pubmed/19858407>