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Chronic Kidney Disease among First Nations People in Alberta:
Prevalence, Health Services Utilization and Access to Quality Care

by

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ABSTRACT

Background: The purpose of this study was to determine the prevalence of measured chronic kidney disease (CKD) among First Nations people in Alberta. We also examined whether the likelihood of a nephrologist visit differed for First Nations versus non-First Nations people with severe CKD, and assessed whether access to health care and management of CKD differs for these two groups with CKD based on hospitalization rates for CKD relevant ambulatory care sensitive conditions (ACSC).

Subjects and Methods: Computerized laboratory data was used to identify out-patients 20 years of age or older with at least one serum creatinine measurement during a six-month period (July 1, 2003 to Dec 31, 2003) in Alberta, Canada. We calculated the age and sex standardized period prevalence of measured CKD for First Nations and non-First Nations. Access to ambulatory care was measured by assessing likelihood of a nephrologist visit for patients with $\text{GFR} < 30 \text{ mLmin}/1.73 \text{ m}^2$ using logistic regression model, and rate of hospitalizations for a CKD relevant ACSC using negative binomial regression models, for First Nations compared to non-First Nations.

Results: A total of 70,601 subjects with CKD were identified. The age and sex adjusted prevalence of measured CKD was 4.45% among non-First Nations and was 4.16% among First Nations. First Nations with more severe CKD were less likely to visit a nephrologist (OR 0.63; 95% CI 0.40 - 0.99). After adjustment for sex, age, diabetes and GFR, First Nations were more than twice as likely as non-First Nations with CKD to be hospitalized for an ACSC (rate ratio 2.59; 95% CI 1.76 - 3.81).

Conclusions: First Nations with CKD had reasonable access to GPs, but a trend towards reduced access to a nephrologist. They were also twice as likely to be hospitalized for a CKD

relevant ACSC. These results suggest that there may be potential inequities in either access to specialized health care for First Nations with CKD, management of this chronic condition by the health care system or the patients' themselves, or an overall poorer health status of First Nations with CKD.

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DEDICATION

To my parents who have always encouraged me in pursuing higher education.

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LIST OF ABBREVIATIONS AND NOMENCLATURE

ABBREVIATIONS

DEFINITIONS

ACSC	Ambulatory Care Sensitive Conditions
AHW	Alberta Health and Wellness
CKD	Chronic Kidney Disease
DA	(census) Dissemination Area
DKML	Dynacare Kasper Medical Laboratories
ESRD	End-Stage Renal Disease
FNIHB	First Nations and Inuit Health Branch (of Health Canada)
FNs (in tables and figures)	First Nations
GFR	Glomerular Filtration Rate
GP	General Practitioner
MDRD	Modification of Diet in Renal Disease (Study)
NARP and SARP	Northern and Southern Alberta Renal Programs
NDSS	National Diabetes Surveillance System
NHANES	National Health and Nutrition Examination Survey
PHN	Personal Health Number

**Chronic Kidney Disease among First Nations People in Alberta:
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BACKGROUND

1.1 Aboriginal and First Nations People: Terminology and Demographics in Canada

Aboriginal is a collective term incorporating three groups of individuals: Indian, Inuit and Métis. Since the 1970s, the term First Nations has been adopted to replace the word "Indian" in Canada (1). According to the 2001 Canadian Census (2), Aboriginal people represent approximately 3.3 % of Canada's total population, with 62.4 % of Aboriginal people of First Nations descent. The western provinces (Alberta, Saskatchewan and Manitoba) have the highest proportion of Aboriginal people in Canada, with 5.3% of Alberta's population (about 156,225 individuals) of Aboriginal descent (see **Appendix 1**).

First Nations people are further categorized as "Registered First Nations" and "non-Registered First Nations". Registered refers to those First Nations people who, under the federal Indian Act, are entitled to Treaty rights, and who are registered under the federal Indian Act (3). To be eligible for registration individuals' must meet certain criteria specified by the act (based on their personal histories) and apply to the Government of Canada. The focus of this study was Registered First Nations. Aboriginal people not classified as Registered First Nations, including First Nations people who do not have Treaty rights under the federal Indian Act (non-Registered First Nations), as well as the Inuit and Métis population, were included in the comparison group for the purposes of this

research. Based on data from Statistics Canada, and as shown in **Appendix 1**, the majority of Aboriginal people in Alberta in 2001 (54.4%) were identified as First Nations. Statistics Canada sources indicate that there were 80,775 Registered First Nations in Alberta in 2001 (**Appendix 2**), with 45% of the Registered First Nations population living on-reserve. Among the Registered First Nations who lived off-reserve, 77.7 % lived in urban areas.

1.2 Aboriginal People and Health Status

Recent studies that have looked at key indicators of the relative health of populations have consistently demonstrated the poor health status of Canadian First Nations people (4), with a life expectancy of First Nations people seven years less than the general Canadian population (5), and an infant mortality rate twice as high (6). Not only do these indicators demonstrate poor health status, but data from the 1994/95 National Population Health Survey (NPHS) also showed that Aboriginal people more frequently rated their health poorly as compared with the general population (7).

Health disparities among Aboriginal people are present across the spectrum of diseases. Aboriginal people had traditionally been thought to have a low prevalence of chronic diseases, including chronic kidney disease (CKD), with injuries and infectious disease the primary causes of morbidity and mortality (6;8). However, as a result of significant social, economic and cultural changes in the past several decades, the health status of Aboriginal people has been negatively affected by chronic conditions (such as cardiovascular disease and cancer), while the population has also continued to experience higher rates of infectious disease (8-10). The prevalence of all self-reported major chronic diseases from the 1999 First Nations and Inuit Regional Health Survey was significantly higher in Aboriginal communities compared with the general Canadian population (9;11).

Aboriginal people are also significantly disadvantaged in terms of social determinants of health, such as housing, education, employment and income. Registered on-reserve First Nations people average four persons per dwelling compared to less than three persons for non-Aboriginal populations (12). Aboriginal people are also less likely to complete all levels of education, and have a significant higher unemployment rate and a lower annual income (9). In Alberta, 47.2 % of Registered First Nations people had an annual income of less than \$12,000 per year in 2000 (13).

1.3 Chronic Kidney Disease among Aboriginal People

1.3.1 Definition of chronic kidney disease

Chronic kidney disease (CKD) is typically a slowly progressive chronic condition, and usually results from diseases that cause a gradual loss of kidney function, such as diabetes, hypertension, and vascular disease. Kidney function is best assessed by glomerular filtration rate (GFR), which can be estimated from serum creatinine measurements. The National Kidney Foundation has defined five stages of kidney disease based on the estimated GFR (14): stage 1 (Kidney damage with normal or increased GFR; $\text{GFR} \geq 90 \text{ mL/min/1.73 m}^2$); stage 2 (Kidney damage with mild decrease in GFR; $\text{GFR} 60\text{-}89 \text{ mL/min/1.73 m}^2$); stage 3 (moderate decrease in GFR; $\text{GFR} 30\text{-}59 \text{ mL/min/1.73 m}^2$); stage 4 (severe decrease in GFR; $\text{GFR} 15\text{-}29 \text{ mL/min/1.73 m}^2$); and stage 5 (kidney failure; $\text{GFR} < 15 \text{ mL/min/1.73 m}^2$ or dialysis). CKD is defined as either kidney damage or $\text{GFR} < 60 \text{ mL/min/1.73 m}^2$ for greater than 3 months (14). Patients with stage 5 CKD commonly require renal replacement therapy (i.e., dialysis or kidney transplantation).

With respect to etiology, diabetes and renal vascular disease are the two most common causes of CKD and end-stage renal disease (ESRD). ESRD is an important health problem, because of its increasing prevalence and poor clinical outcomes. Patients with ESRD have an annual mortality rate that approaches 20% (15), and suffer significant morbidity, including cardiovascular disease. As a result, and due to the need for dialysis, patients with ESRD experience poor quality of life (16;17). Moreover caring for patients with ESRD is resource intensive, with annual health care costs ranging from CAN\$43,193 to CAN\$74,316 per dialysis patient in Alberta in 2000 (18).

While development of CKD is usually silent, it can be detected through routine measurement of serum creatinine. This is important since adverse outcomes associated with CKD can be prevented, and the progression of CKD delayed, through early detection and treatment (14). Moreover, delayed referral to a nephrologist has been associated with increased mortality even among those patients who survived their first year on dialysis (19). As such, the National Kidney Foundation has released treatment recommendations that include referral to a nephrologist for all patients with a $GFR < 30 \text{ ml/min/1.73m}^2$. For patients identified as having a $GFR < 30 \text{ ml/min/1.73m}^2$, therefore, it is important for patients to have adequate access to appropriate health care in order to control the progression of the CKD and reduce other adverse health complications associated with CKD.

1.3.2 Kidney disease among Aboriginal people

There have been very few studies examining CKD among Aboriginal people, particularly with respect to documenting the extent of early kidney disease. To the best of our knowledge, there have been no studies that provide estimates of the prevalence of CKD

among Aboriginal People in Canada or the U.S. To date, studies of kidney disease among Aboriginal people have focused on 1) diabetes (20-29), which is the most common cause of ESRD among Aboriginal people, accounting for over 50% of cases in Canada (30), or 2) the prevalence of ESRD among Aboriginals (31).

Given the high prevalence of ESRD due to diabetes, the prevalence of diabetes among Aboriginal people becomes important to recognize, to estimate the potential extent of CKD secondary to diabetes. According to the 1991 Aboriginal Peoples Survey (APS), in Canada the prevalence of diabetes among Aboriginal people is at least three times the national average, with high rates occurring in all age groups (20). A point prevalence study using survey data for all Saskatchewan reserves in 1990 showed that age-adjusted rates of diabetes mellitus were higher among Saskatchewan First Nations adults (9.7%) than among non-First Nations adults (6.1%) (27). This difference was magnified further in sex-adjusted analyses. A study in Manitoba also showed considerably higher prevalence of diabetes among Aboriginals (32). Not only do Aboriginal people have a higher prevalence of diabetes, but they are also more likely to experience diabetes-related complications (20), with rates of diabetic nephropathy ranging from 25-60% (33). The ten year incidence rate of ESRD due to diabetes among all First Nations age groups was noted to be 16.2 times higher than the rate of ESRD due to diabetes among the general population in Saskatchewan. After accounting for the higher prevalence of diabetes, First Nations people with diabetes were still six times more likely to manifest ESRD due to diabetes compared to the general population (34).

Canadian Aboriginal people overall have experienced ESRD at rates 2.5 to 4 times higher than those found in the general population (35). In Saskatchewan between 1980 and 2000, the prevalence of Aboriginal patients on dialysis increased eight fold (35). These

findings suggest that the problem of CKD resulting in ESRD is common among Aboriginal people in Canada.

Although studies on the prevalence of CKD among Aboriginal people are not available in the literature, studies have suggested increased rates of kidney disease among the Aboriginal population in both diabetics and non-diabetics, as evident by urinary albumin excretion rates (36). The Strong Heart Study (37), a longitudinal population-based study of cardiovascular disease risk factors among American Indians, has shown high rates of abnormal urinary albumin excretion in all Aboriginal communities. A large proportion of the study population (53%) had diabetes, which may account for the increased rates of albuminuria. However, even among subjects without diabetes, the prevalence of abnormal albuminuria ranged from 10 – 20%. Another population-based, cross-sectional survey, the Zuni Kidney Project in New Mexico (38), also showed increased albuminuria excretion rates among the non-diabetic Zuni Indian population.

These previous studies have only estimated the prevalence of albuminuria among Aboriginal people outside Canada, and have not provided information on the prevalence of CKD. Given that it is possible that the increased incidence of ESRD noted among First Nations could have resulted from an increase in the proportion of patients with CKD, an increase in the rate of their disease progression, or decreases in competing mortality (39), a study documenting the prevalence of CKD among First Nations people is critical.

1.4 Health Care Use and Access to Quality Care

1.4.1 Theoretical model of access and its appropriateness for Aboriginal population

One of the tenants of the Canada Health Act is the principle of equal access to medically necessary services, based only on need (and not on other factors such as wealth, racial origin, or the region in which people live). This has consistently been rated as a high priority by Canadians, and its importance has recently been reaffirmed by the Romanow report (40). Noting this, policy makers are obliged to ensure equal access to the health care system for various groups in the population (41), with an aim to improve the health condition of the population, including Aboriginal people. Access to health care, therefore, can be seen as an important quality indicator for a health care system.

Unfortunately, there is no straightforward measure to operationalize this concept of access to care. The intermediate health outcome indicators (i.e. use of health services), which influences the outcomes of health status and consumer satisfaction, is a benchmark of health policy regarding “access”, and has been used as a surrogate measure of access (41). The behavioral model of health service utilization developed by Aday and Anderson is one of the frequently used frameworks for analyzing the factors that might be associated with patient utilization of health care services and access to health care. A systematic review published in 1998 reported that 139 papers used this model between 1975 and 1995 to study health care utilization (42). According to the original and subsequently revised framework for access to health care, achieving change in health behavior (i.e., use of health services) depends on three primary determinants of health behavior including: 1) the characteristics of the health delivery system, 2) the population, and 3) the external environment.

The *characteristics of the health delivery system* are represented by resource factors (e.g. the invested labor and capital) and organizational factors (including both entry to the system such as waiting time and travel time, and passage through the system such as

treatment received and who the patient sees). The *characteristic of the population* include predisposing factors (i.e. demographic factors, education, occupation, *ethnicity*, and health beliefs), enabling factors (e.g. income, health insurance, and physician supply in a community) and needs factors (e.g. perceived and evaluated health). The *external environmental factors* reflect the economic climate, relative wealth, politics, level of stress and violence, and the prevailing norms of society (41-43).

The intermediate health outcome indicators (i.e. use of health services) may also be characterized and measured in terms of their type, site, purpose and time interval involved. When measuring the time interval for a visit, it is important to distinguish “initiation” and “continuation”, as they measure who gets into the system and how often they use it, respectively (44). One practical suggestion regarding this issue was to use a multi-stage approach, by first analyzing the probability of use versus no use, and then among users to explore the amount of use (45;46).

This model has moved beyond the traditional medical epidemiology that primarily considers individual risk factors and behaviors. It also includes social determinants of health and illness and has translated this political concept of “access” into a complex, multidimensional health policy measure. One dimension of access developed using the concept from the model was “equitable access”, which was defined by Andersen as occurring when demographic and need variables account for most of the variance in utilization (47). “Inequitable access occurred when social structure (e.g., ethnicity), health beliefs, and enabling resources (e.g., income) determine who gets medical care” (43). Given the broad social context that the model encompasses, it is particularly relevant to issues regarding access among Aboriginal people who are experiencing historical, social, economic, cultural and political inequities in health (9). However, the behavioral model is

merely a theoretical framework for analyzing the factors rather than providing a mathematical model with precise variables or providing precise methods to be used. The choice of factors depends on the extent of prior research, the research question, the purpose of the study, and data availability (42). We were able to measure some of the components of the Aday and Anderson model within the context of our study, and therefore we will use it as a guide for interpretation of results.

1.4.2 Impact of ethnicity on health services utilization

The behavioral model of health services utilization developed by Aday and Anderson (41-43), as described above, is a model that applies to the entire population irrespective of race. The impact of ethnicity, and factors relating to ethnicity, may be more relevant in understanding the complex issue of health service use for the Aboriginal population. Although we were unable to measure many of the components of Aboriginal ethnicity, it is important to review and understand these concepts to aid in interpretation of the study results.

Ethnicity is a concept referring to a shared culture and way of life (48), and is defined by social rather than genetic characteristics. These social variables that make up ethnicity may be important in determining differences in health status (49). For example, the appearance of a highly consistent pattern of differential mortality between races may be ascribed to environmental (that is, social), not genetic factors (49). Ethnicity covers two heterogeneous underlying factors, societal factors and cultural/ethnic factors. Societal factors refer to factors that are external to the individual and cultural/ethnic factors refer to individual-level behavior (50).

Factors relating to ethnicity which are used to explain disparities in health and health care use are categorized into three levels, namely patient, healthcare systems, and provider level variables. However, the three levels are not isolated from each other, rather the interactions between the variables are essential for their co-existence in the system.

Patient level variables that are relevant to this particular study include patients' preferences, minority patient mistrust and experiences of discrimination, and treatment refusal. Patients' beliefs and values and other psychological characteristics influence the level and type of care they receive, and influence their willingness to accept physicians' recommendations (51;52). Studies have reported that minority patients are more likely to refuse treatment recommendations (53), adhere poorly to treatment regimens, and delay seeking care (52;54). These health care seeking behaviors and attitudes can develop as result of poor prior interactions with the system, mistrust of health professions that stems from racial discrimination and the history of inferior care for minorities, or lack of knowledge of how to best use health care services (51;52).

Health system level variables reflect the manner in which the health care system is organized, financed and delivered. Factors relating to ethnic minorities that are relevant to this particular study include lack of interpreters and translation services to help people overcome language, cultural and knowledge barriers when seeking care (51;52), as well as time pressures on physicians that may hamper their ability to accurately assess medical conditions when cultural and linguistic barriers are present (51;52). In addition, ethnic minorities report greater difficulties in obtaining referral and accessing specialist physician care (51;52), which may be related to the organization of the health care system. These findings have been reported in patients with kidney disease as well. In a national prospective cohort study conducted in 81 dialysis facilities throughout the United States the

researches found that late referral to nephrologists was more common among African-American men than white men (44.8% vs. 24.5%; $P < 0.05$) (55). They also found that the risk of death was greater among patients with late referrals. Therefore issues of access to specialized care for patients with CKD are particularly relevant and will be a focus of this study.

Provider level variables may include bias against minorities, greater clinical uncertainty when interacting with minority patients, and beliefs held by the physicians about the behavior or health of minorities. Although no direct evidence shows provider biases affect the quality of care for minority patients, studies have found physicians' diagnostic and treatments decisions are influenced by patients' race or ethnicity (51). The response to these physician attitudes and behaviors is that of mistrust by the minority patients (51).

1.4.3 Health Services Use, and Factors Associated with Health Services Use, among Aboriginal People

Responsibility for health care for Registered First Nations people is within the Federal Government's domain and is administered through provincial or territorial health plans. There is limited data in the literature which describes utilization of health services among Aboriginal people. Based on data from the Canadian Prairie Provinces, the primary indication for physician visits for First Nations people in 1996-97 were for diseases of the respiratory system, followed by injuries and poisonings. The hospitalization rates for the same causes among First Nations people were about two-and-half times higher than the general Canadian population (56).

Available literature from Canada would suggest that there is considerable variation in physician utilization by Aboriginal people, depending on whether the source of data is self report or computerized administrative data. Data from the 1991 Aboriginal Peoples Survey and the 1991 General Social Survey suggest that Aboriginals as compared with the general Canadian population were less likely to report consulting a physician for asthma, heart conditions, diabetes and high blood pressure (57). However administrative data from Alberta Health and Wellness suggests that Aboriginal people used more physician services for diabetes, mental illness, injuries and respiratory diseases as compared with the general population (13).

Specialist physician services in particular appear to be consistently utilized less by Aboriginal people. According to the Assembly of First Nations, a 2002 opinion poll of the National Aboriginal Health Organization suggested that less than half of the Aboriginal population surveyed reported easy access to specialist services (58). A recent study from Manitoba provides further support for these disparities in specialist health service use. Administrative data from Manitoba was used to compare Registered First Nations people with all other Manitobans for five health services indicators for the fiscal year 1998/99. The results of this study showed that the hospital separation rate was more than double, and the total days of hospital care per capita was 1.7 times greater, for First Nations compared to non-First Nations in Manitoba. While the ambulatory visit rate was 1.3 times higher for First Nations people, the specialist visit rates (both initial consult and follow-up) were lower (0.895 vs. 1.284 per person; $p < 0.05$) (59). These findings, based on both self report and administrative data, suggest a lack of access to specialist physician services for First Nations people.

The patterns of health care use among Aboriginal people (increased rates of general practitioner [GP] visits and hospitalizations, with decreased use of specialist physician services) may be different from other visible minority groups in Canada, as suggested by one recent study using Canadian Community Health Survey data. Although the researchers excluded Aboriginal people from the study, they found that ethnic minorities (which included Chinese, Japanese/Korean, South Asian, Filipino/Southeast Asian, Arab/West Asian, Black and Latin American) used as many as GP and specialist services as whites, but had fewer hospital admissions (60).

Specific factors including rural location of residence and lower education may impact Aboriginal peoples' use of health services, and have been reported to be barriers to use of physician services for Aboriginal people in Canada (57). In the United States both the increased availability of medical providers and urban residence were strongly associated with the higher use of health care by American Indians (61).

Factors of ethnicity (i.e., Aboriginal origin) that affect health care use have not been well studied. However, factors such as patients' beliefs, attitudes, experience and social interaction, have also been reported as influencing the decision making in seeking health care (62;63).

It has been proposed that the increase in ESRD among Aboriginal people has been driven by the high prevalence of diabetes and vascular diseases (10;64). However, the potential that there are barriers in access to quality health care that may adversely affect the progression of CKD and contribute to the higher prevalence of ESRD seen in Aboriginal people, is a possibility that also needs to be addressed. Limited research has examined access to health care for Aboriginal people, especially in Canada. To the best of our knowledge there has been no research conducted to examine the issue of access to

appropriate CKD care among Aboriginal people with CKD, which is the objective of this study.

1.4.4 Direct and indirect measures of access to health care

The actual utilization of ambulatory care services, which includes all types of health services that are provided on an outpatient basis, has been the most commonly adopted measure of access to health care (41;61). Given that the population (see section 2.2) under investigation included subjects who already had initial access to a physician (as they had obtained a serum creatinine measurement) our study instead focused on visits to nephrologists for subjects with more severe CKD as a primary outcome measure of access. We used Aday and Anderson's framework as a guide to understand the issue, and to look at factors that affected access to health care. Differences in the likelihood of visits to specialists for patients with $\text{GFR} < 30 \text{ mL/min/1.73 m}^2$ would suggest potential differential access.

Another indirect measure or indicator of access and overall performance of the health care system is hospitalization for ambulatory care sensitive conditions (ACSC) (65-70). The theoretical concept of ACSC was developed by Billings et al., and refers to conditions that, if managed timely and effectively in the outpatient setting, would have a reduced likelihood of hospitalization (71). Although ACSC are based on hospital inpatient data, they provide insight into the quality of care in the ambulatory care setting. It is assumed that individuals with these conditions who are unable to obtain or have inadequate access to care experience delays in both diagnosis and treatment for these conditions (72). As such, higher rates of hospitalization for ACSC is believed to be associated with inadequate access to ambulatory care or ineffective management of these conditions (73).

ACSC categories have been developed by advisory panels of experts in different studies. ACSC have been identified for various clinical conditions including asthma, angina pectoris, pelvic inflammatory disease, immunization preventable infections, otitis media, gastrointestinal ulcer, malignant hypertension, and congestive heart failure (66). However, the ability of appropriate ambulatory care to reduce the risk of hospitalization due to ACSC differs according to the specific clinical condition. Given this, the selection of the ACSC should be adapted to the context of each study, specific to the clinical condition, to guarantee validity and reliability (74). For the purposes of our study we developed and examined hospitalizations for ACSC that were particularly relevant to CKD. A detailed discussion of the development and definition of the CKD related ACSC is provided in the Methods section.

1.5 Summary and Overview of Study

In summary, little research has been undertaken examining the prevalence of CKD among First Nation people and exploring issues related with access to health care for First Nations people with CKD, particularly in Canada. Moreover, no research has been done examining health service utilization among First Nations people with CKD. Therefore, the objective of this study was:

- 1) To determine whether there was a difference in the likelihood of a visit to a nephrologist for First Nations and non-First Nations people with a GFR < 30 mL/min/1.73 m² in Alberta.
- 2) To determine whether access to quality care differs for First Nations and non-First Nations people with CKD in Alberta.

We hypothesized that, compared to non-First Nations, First Nations would have a lower likelihood of a visit to a nephrologist and higher rates of hospitalization for a CKD relevant ACSC.

METHODS

2.1 Data Sources

This research is part of a larger long-term initiative designed to create a laboratory-based network of chronic kidney disease in Alberta. Specifically, funding has been acquired to establish a province-wide laboratory-based network to capture all people in Alberta who have a serum creatinine measured by any laboratory located in Alberta's 9 health regions. At the time this analysis was performed, laboratory data was only available from 6 of 9 health regions. The following data sources were used in this study, with data linkage of different sources as illustrated in Figure 1:

2.1.1 Laboratory data and serum creatinine measurements

Computerized laboratory data from six of the nine Health Regions (see **Figure 2** for map) in Alberta, namely the Palliser, Chinook, Calgary, Capital, Peace Country and Northern Lights Health Regions were used to identify all out-patients 20 years of age and older who had at least one serum creatinine measurement during the six-month time period July 1 2003 to December 31, 2003. These six Health Regions include 74 of the 109 First Nation reserves, and contained approximately 69.1% of the First Nation population in Alberta (see **Figure 3** for map of First Nations communities in Alberta), and approximately 83% of the non-First Nation population in Alberta. An estimate of GFR was obtained from a prediction equation which includes the person's serum creatinine, as described below.

Serum creatinine measurements may be performed using different assays by different laboratories, resulting in variations in measurements across laboratories. In order

to assess this potential variation in measurements, and as a component of our ongoing research, Dynacare Kasper Medical Laboratories (DKML) in Edmonton conducted a survey by sending out serum creatinine pools to the major laboratories across the province. The creatinine measurements obtained from the laboratories across the province were compared to the Beckman CX3 analyzer at DKML, which was the original assay used in the development of the MDRD GFR equation. Overall the “harmonization” of serum creatinine measurements across the province was excellent. The only region which appeared to have a systematic error in measurement was the Calgary Health Region, where serum creatinine measurements were consistently 7 μ mol/L lower than the standard. We therefore added 7 μ mol/L to each serum creatinine measurement in the Calgary Health Region prior to implementing the MDRD GFR equation.

2.1.2 Computerized data from Alberta Health and Wellness (AHW)

Alberta Health and Wellness collects data in several domains (75), including:

- a) Alberta Health Care Insurance Plan Registry – contains date of birth, gender, postal code at year end, recipient unique identifier (Personal Health Number [PHN]) and Registered First Nations Status.
- b) Ambulatory Care Records – contains records on day surgeries, some day procedures, emergency room visits, recipient unique identifier (PHN), provider, and 16 diagnostic codes and 10 procedure codes. All diagnosis and procedures are coded using ICD-9-CM, until March 31, 2002, and ICD-10-CM codes from April 1, 2002 forward. Data is available from 1994/95 onward.
- c) Alberta Health Insurance Plan Payment Data – contains claims submitted for payment by Alberta service providers, including physicians, for services provided to

Alberta registrants. The variables included in this database include recipient unique identifier (PHN), as well as provider and service details. Data is available from 1973/74 onward.

d) Inpatient Hospital Morbidity Data - contains details regarding inpatient hospitalizations including recipient unique identifier (PHN), admission/discharge dates, length of stay, facility, 16 discharge diagnoses and 10 intervention codes and suffixes. ICD-9-CM coding was used until 2001/02, following which ICD-10 was implemented. Data is available from 1988/89 onward.

Data for each subject identified from Regional laboratories was linked by the unique Alberta Personal Health Number (PHN), in a confidential manner, to AHW to identify the First Nations status and to obtain details regarding health care resource use and postal code, as outlined below.

2.1.3 2001 Canadian Census data

Data from the 2001 Census was used to obtain an estimate of household income and location of residence. The 2001 Census variables include count and demographic data including usual place of residence, schooling and income. For the purposes of this study the residential postal code for each study subject was linked to the 2001 Census data using the Postal Code Conversion File at the level of the census dissemination area (DA). Data at the level of the DA was used to provide average household income levels and define rural residence for people identified with CKD.

2.1.4 The Northern and Southern Alberta Renal Programs (NARP and SARP)

The NARP and SARP contain detailed information on all pre-dialysis, dialysis and kidney transplant patients in the province under the care of a nephrologist. Subjects with a kidney transplant prior to their Index Date were identified from these programs and excluded from the study.

2.2 Study Population

2.2.1 Inclusion criteria

Computerized laboratory data was used to identify all out-patients 20 years of age and older who had at least one serum creatinine measurement, recorded in an out-patient setting, during the six-month time period July 1, 2003 to Dec 31, 2003. The index GFR was estimated from the subjects' first recorded creatinine measurement (Index GFR) according to the following formula (MDRD GFR) (76) :

$$\text{GFR} = 186 \times [\text{Pcr}] \exp(-1.154) \times [\text{age}] \exp(-0.203) \times 1.212 \text{ (if black)} \times 0.742 \text{ (if female)}.$$

This equation was modified to exclude the variable “race” given the inability to identify African Americans from the data source. This will minimally affect the estimation of GFR, and is unlikely to bias the results for the general population, given that only 1 % of the Alberta population is reported to be “Black” (77). The MDRD GFR has been validated in the Aboriginal population (78), and a community based population without kidney disease (79).

Study subjects were categorized as “Registered First Nations Status” and “Non-First Nations”. *Registered First Nation Status* was identified by linking to the Alberta Health and Wellness registry file. Registered refers to First Nations people who, under the federal

Indian Act, are entitled to Treaty rights and who are registered under the Indian Act (3). The federal government is responsible for the health care of First Nations people, which is administered through the First Nations and Inuit Health Branch (FNIHB) of Health Canada. FNIHB determines Registered First Nations Status through the Department of Indian and Northern Affairs, which maintains an electronic database of all registered individuals with First Nations Status. The FNIHB subsequently pays the Alberta Health Care Insurance Plan premiums for all Registered First Nations people in the province of Alberta. As a result of this process, individuals with Registered First Nation Status are identified in the registry file of Alberta Health and Wellness. Aboriginal people not classified as Registered First Nations, including First Nations people who do not have Treaty rights under the federal Indian Act (non-Registered First Nations), as well as the Inuit and Métis population, were included in the comparison group for the purposes of this research. Given the small number of Aboriginal people not classified as Registered First Nations, compared with the large number of non-Aboriginal patients, the inclusion of non-registered Aboriginal patients in the comparison group is unlikely to influence the results of our analysis. The Registry file for the time period 1993/94 to 2003/04 was used to determine Registered First Nations Status. An individual who at any point during this time period was identified as Registered First Nations was defined as “First Nations” for the purpose of this study. All other individuals in the registry file were categorized as “Non-First Nations”.

2.2.2 Exclusion criteria

a) Creatinine values < 25 $\mu\text{mol/L}$. These creatinine measurements were excluded as these results are not clinically plausible, and likely reflect errors in lab results.

b) Subjects with ESRD on dialysis at the Index Date. The focus of the study was on access to medical care among the patients with CKD, therefore patients with ESRD (i.e. irreversible kidney failure) prior to their index date were excluded. The index date was defined as the date of the first serum creatinine measurement and corresponding GFR during the time period July 1 2003 to December 31 2003. Patients with ESRD on dialysis were identified from the AHW physician claims file. The physician claims database was searched from July 1, 2001 to the Index date for each subject to identify billing claims for dialysis (ICD9 codes: 13.99A, 13.99B, 13.99C, 13.99D, 13.99O). These claims were ordered chronologically and individuals whose period of dialysis treatment was at least 90 days were identified and excluded. This method of identifying patients with ESRD on dialysis using administrative data has been used in other studies (80).

c) Subjects with a kidney transplant prior to their Index date. Subjects identified from the NARP and SARP programs as having had a kidney transplant prior to their index date were also excluded.

d) Out of province-patients. Due to the inability to monitor health services utilization for out of province patients, only patients with a valid Alberta PHN were included.

2.3 Study Period

The study period and timeframe for assessment of physician visits (including nephrologists, cardiologists, general internists and GPs), emergency room visits and hospitalizations was from the Index Date to March 31, 2005.

2.4 Measures of Access to health care

We hypothesized that there were differences in access to health care and management of CKD for First Nations and non-First Nations people with CKD in Alberta. To assess this we explored patterns of health care resource use, including visits to GPs and specialist physicians (nephrologists, cardiologists and general internists), as well as frequency of emergency room visits and hospitalizations. We further examined the likelihood of a nephrologist visit for patients with $\text{GFR} < 30 \text{ mL/min/1.73 m}^2$ (patients who should, based on published guidelines, be seen by a nephrologist) as well as the likelihood of hospitalization for CKD relevant ACSC for First Nations compared to non-First Nations with CKD. Use of these different measures was undertaken to provide a more comprehensive picture of access to quality health care and management of CKD for the two study groups. The variables used in this study are detailed below.

2.4.1 Access to CKD care

a) The likelihood of a visit to a nephrologist (yes/no)

The likelihood of a visit to a nephrologist was examined for subjects with a $\text{GFR} < 30 \text{ mL/min/1.73 m}^2$. A visit to a nephrologist was defined as any visit to a nephrologist during the study period, as identified from the AHW physician claims data.

b) Hospitalizations for CKD relevant ACSC

As stated, we wished to measure the differences in hospitalization rates for CKD related ambulatory care-sensitive conditions (ACSC) for First Nations and non-First Nations people with CKD. As discussed in the review of the literature, ACSC are conditions that could ideally be managed in the outpatient setting, and hospitalization for

these conditions may indicate a potentially preventable complication resulting from inadequate access to quality health care.

As a list of CKD relevant ACSC had not been developed, we implemented a Delphi Process to establish these conditions. The key features of the process included: anonymity for all respondents; iteration with controlled feedback; and statistically interpretable group response (81). We implemented the Delphi Process in the following 3 Stages:

Stage 1: a group of 12 nephrologists in the Division of Nephrology in Calgary were selected as the 'expert panel'.

Stage 2: panel members underwent three Delphi rounds to develop a list of CKD relevant ACSC. The first round was unstructured, and panel members were asked for their opinions regarding CKD relevant ACSC based on a list of potential ACSC presented by the researchers. A questionnaire with a modified list of potential ACSC was then constructed based on the first round results. This questionnaire was sent to all panel members at the second Delphi round, and members were asked to rank the relevancy (yes/no) of the ACSC to CKD care (i.e., could high quality outpatient CKD care have avoid the need for a hospitalization). Percentage agreement was determined for each condition. A second questionnaire including the potential ACSC and the group response from the first questionnaire was sent back to the panel members for a second ranking of relevancy (on a scale of 1 to 10);

Stage 3: a final list of CKD-related ACSC was defined based on the mean relevancy score for each candidate condition by all panel members from the second questionnaire. The acceptable relevancy score was 7.22, which represented the average relevancy scores for all conditions. The final list of CKD relevant ACSC conditions (**Table 1**) was consistent with

the expert panels from other studies of chronic disease, except for two conditions specific to CKD, namely volume overload and hyperkalemia (66).

An ACSC hospitalization was defined as any admission to hospital for a CKD relevant ACSC as determined by the primary hospital discharge diagnosis code (ICD10) during the study period (Index Date to March 31 2005).

2.4.2 Ambulatory health service utilization

a) General Practitioner (GP) visits: A GP visit was defined using the AHW physician claims database for the study period. We examined GP visits for all conditions and chronic disease related visits separately:

1. The broadest definition was a GP visit, irrespective of the indication for the visit.
2. Sub-analyses considered only GP visits for chronic diseases including renal related conditions, diabetes related conditions, and vascular related conditions, respectively (see definitions in **Appendix 3**).

b) Specialist visits: A specialist visit was defined separately for nephrologists, cardiologists and general internists using the AHW physician claims database, as these specialties were most relevant to CKD management. The total number of out-patient visits to each type of specialist was calculated for the study period.

c) Emergency room visits: A visit to the emergency room, irrespective of the indication, was determined using AHW Ambulatory Care Database for the study period.

d) Other variables used in the study:

- **Kidney Function** was classified into 3 categories according to the Index GFR (mL/min/1.73 m²): GFR \geq 60, GFR 30 -59 and GFR <30 (patients not yet on dialysis).
- **Diabetes Mellitus** was defined as 2 or more physician service claims for diabetes (ICD-9 code 250) within a 2-year period, or 1 or more hospitalizations with a diabetes code as the primary, secondary or tertiary diagnosis using the AHW physician claims and hospitalization data files respectively. This algorithm is highly specific for diabetes (82), and is the accepted and validated definition used by the National Diabetes Surveillance System (NDSS). Diabetes was categorized as *present* or *absent*.
- **Income Levels and Rural/Non-Rural Residence:** Patient income levels were determined using the residential postal code for each study subject and the postal code conversion file program (83) from the 2001 Census Canada data. This program utilizes a subject's residential postal code as the input data, and then automatically assigns each subject to a corresponding neighborhood income quintile. Neighborhood income per person equivalent is a household size-adjusted measure of household income, based on the 2001 census summary data at the DA level, which uses person-equivalents implied by the 2001 low income cut-offs (83). Since households in the lowest income quintile are smaller on average than households in the largest income quintile, data are adjusted for household size to allow for more realistic comparisons. This adjustment reflects the principle that household size and composition (number of adults and children) affect household needs (84). The same program was used

to determine rural location of residence, which was defined by a community population size $< 10,000$. In Canada, communities of up to 10,000 are often classified as rural (85).

- **Distance to physicians:** Both potential and actual distances to physicians were calculated. The potential distance to the nearest physician office location (GP, nephrologist and general internist) was defined as the direct distance following the earth surface between a subject's residential postal code and the office postal code of the nearest physician. Among the subjects that had a GP, nephrology or general internist visit, the actual distance between their residential postal code and the postal code of the physician they visited most frequently during the study period was also calculated. The most frequently visited physician for each subject was determined by comparing the total numbers of visits to each service location using the physician claims data. All distances were calculated using ArcView 3.3 version software. GP postal codes were obtained from the Southam Database (85), nephrologist postal codes were obtained from NARP and SARP, and general internist postal codes were obtained from the Alberta Medical Association. Given concerns about the accuracy of the general internist postal codes from the Alberta Medical Association each address was verified as being correct by using the Physicians Directory and/or by telephone contact with each office directly.

2.5 Ethics Approval

The study was approved by the Ethics Review Board of the University of Calgary (see **Appendix 4**).

2.6 Data Analysis

Univariate analysis was conducted initially to examine the distribution of each variable considered in the study. When appropriate, the continuous variables, such as age and GFR, were categorized to enable between-group comparisons. Bivariate analysis was used to explore any possible association or correlation between the variables. Chi-square and non-parametric (rank-sum) tests were used to compare the characteristics of the First Nations group with Non-First Nations group.

The following analyses were then carried out:

2.6.1 Proportion of population having at least one creatinine measurement

As an initial assessment of potential access to health care, we calculated the age and sex standardized proportion of the population who had at least one creatinine measurement, for both First Nations and non-First Nations. A Microsoft Excel spreadsheet was used to calculate and plot the proportion of the First Nation and non-First Nation population who had a serum creatinine measurement between July 1, 2003 and December 31, 2003. The numerator was the number of subjects who had at least one serum creatinine measurement between July 1, 2003 and December 31, 2003, and the denominator was the total population in each of the six Health Regions, for First Nations and non-First Nations respectively. Denominator data, stratified by age, gender and First Nations status, was obtained from AHW for the year 2003. The proportion of creatinine measurements was standardized to the age and sex distribution of the 2001 Canadian population by the direct method (86).

2.6.2 Prevalence of measured CKD

The period prevalence of measured CKD from July 1, 2003 to December 31, 2003 for each of the six Health Regions was calculated for both First Nations and Non-First Nations. The numerator was the total number of persons who had a serum creatinine measurement during this time period and were identified as having CKD (GFR < 60 mL/min/1.73 m²) based on an estimate of GFR. The denominator was the total population in the six Health Regions, for First Nations and non-First Nations respectively. The crude age and sex stratified prevalence of measured CKD was plotted using Microsoft Excel. The prevalence was then standardized to the age and sex distribution of 2001 Canadian population by the direct method (86). We also calculated the age and sex standardized prevalence of measured CKD two age groups: under age 65, and age 65 and older.

2.6.3 Description of ambulatory care service utilization

Descriptive analysis was performed regarding ambulatory care use for First Nations and non-First Nations and included visits to GPs for renal, diabetes and vascular related chronic conditions, visits to specialists (nephrologists, cardiologists and general internists) and visits to emergency rooms. For each type of service we first compared the total numbers and proportions of First Nations and non-First Nations subjects who had at least one visit during the study period, and then among the subjects who used the services we calculated and compared the median numbers of such visits.

2.6.4 Modeling access to care

Access to health care was assessed by determining the likelihood of a nephrologist visit for subjects with a $\text{GFR} < 30 \text{ mL/min/1.73 m}^2$, as well as the hospitalization rates for CKD relevant ACSC for patients with CKD ($\text{GFR} < 60 \text{ mL/min/1.73 m}^2$).

a) The likelihood of a visit to a nephrologist (yes/no) for patients with $\text{GFR} < 30 \text{ mL/min/1.73 m}^2$. Logistic regression was used to determine the differences in likelihood of a nephrologist visit for First Nations compared to non-First Nations, after accounting for sex, age quartiles, diabetes (yes/no), income quintiles, and rural location of residence (yes/no). As all independent variables in the model were categorical variables, testing the assumption of linearity of the logit was not necessary.

b) Hospitalizations for CKD related ACSC

Negative binomial regression and the rate ratio were used to compare the risk of hospitalization for a CKD relevant ACSC between First Nations and Non-First Nations with CKD ($\text{GFR} < 60 \text{ mL/min/1.73 m}^2$). Hospitalization was defined as any admission to hospital for a CKD relevant ACSC as determined by the primary hospital discharge diagnosis code during the study period (**Table 1**). We counted all events for patients with multiple events for both First Nations and non-First Nations. Person-time of follow-up was calculated as the total time a subject was not hospitalized during the study period (i.e., duration in hospital was excluded from the person-time). The patient was censored if they died or moved out of the province prior to the end of the study period. We initially intended to use a Poisson regression model to determine the rate ratio for hospitalization between First Nations and Non-First Nations. However, the primary assumption of Poisson regression, that the variance of the data equals its mean, was violated (violation of this

assumption is called overdispersion). A Negative binomial regression model, which corrects for this overdispersion, was therefore used (87). The unadjusted rate ratio of hospitalization for a CKD relevant ACSC was first calculated, and then explanatory variables were examined in the model. The variables assessed were sex, age quartiles, First Nations status (yes/no), GFR levels (GFR < 30 mL/min/1.73 m² or GFR 30 - 59 mL/min/1.73 m²), diabetes (yes/no) income quintiles and rural location of residence.

2.6.5 Statistical software used for the analyses

All analyses were conducted using SAS, version 9.12 (Cary, North Carolina).

RESULTS

3.1 Study Participants

From the laboratory data we identified 388,162 subjects who had at least 1 out-patient serum creatinine measurement between July 1, 2003 and December 31, 2003 (see **Figure 4**). Of these, 905 (0.2%) subjects were excluded because they were not present in the Alberta Health and Wellness registry file, and were presumed to be subjects from out-of-province. We excluded 4,873 (1.3%) subjects less than 20 years of age (this age cut-off was chosen because it matched the age categories in the Census data) and 52 (0.01%) subjects that had a creatinine measurement lower than 25 $\mu\text{mol/L}$ (which likely represented an error in lab data). We also excluded 1,048 (0.3%) subjects who were known to be on dialysis prior to the Index Date and 405 (0.1%) subjects who had a kidney transplant before the Index Date, for a final study population size of 380,879. Two sub-cohorts were constructed for further analysis: a cohort of CKD subjects ($n=70,601$) and a cohort of subjects with both CKD and diabetes ($n=15,389$). The 'Diabetic CKD Population' was formed as management of diabetic conditions are very important for CKD patients.

3.1.1 Full Study Population

Baseline characteristics of all First Nations and Non-First Nations in the study, irrespective of level of kidney function, are presented in **Table 2**. First Nations subjects had a higher median GFR (inter-quartile range) overall at 87.8 mL/min/1.73 m^2 (74.1 – 103.3) compared to non-First Nations at 77.9 mL/min/1.73 m^2 (65.6 – 91.4) ($p<0.001$). Compared to non-First Nations, First Nations people who had at least one creatinine

measurement during the study period were younger, more likely to be female, had a lower household income, were more likely to live in a rural area, and were more likely to have diabetes mellitus. Travel distance to the nearest GP, nephrologist and general internist was significantly longer for First Nations compared to non-First Nations. When the distance to the most frequently visited specialists were compared for those who had actually used the services, the distance for the First Nations population increased further.

3.1.2 CKD Population

Baseline characteristics of First Nations and Non-First Nations with CKD are presented in **Table 3**. Compared to non-First Nations, First Nations appeared to have more severe kidney disease, with a greater proportion having a GFR 15 to 29 (11.2% vs. 6.7%) and a GFR < 15 (5.5% vs. 1.1%). There were similar proportions of males and females among the two groups. Similar to the overall cohort, First Nations people with CKD were slightly younger, had a lower household income, were more likely to live in a rural area, and were more likely to have diabetes mellitus. The potential and actual distances to GPs, nephrologists and general internists were significantly longer for First Nations with CKD compared to non-First Nations.

The geographic distribution of the CKD patients within each of the six Health Regions is shown in **Figure 5**. Eighty six % of non-First Nations with CKD and 65% of First Nations with CKD were from two major urban Health Regions in Alberta, namely Capital and Calgary. As compared with non-First Nations, a higher proportion of First Nations with CKD were from other rural Health Regions, in particular, from Chinook (16%), Northernlights (9%) and Peace Country (11%) Health Regions. This likely reflects the fact that a larger proportion of First Nations people are living in those rural areas.

3.1.3 Diabetic CKD Population

Baseline characteristics of the First Nations and Non-First Nations population with both CKD and diabetes are presented in **Table 4**. First Nations in this sub-cohort had more advanced CKD with 25.2% of First Nations having a GFR < 30 mL/min/1.73 m² as compared with 12.7% in the non-First Nations group. Similar to the overall cohort and the CKD cohort, First Nations with CKD and diabetes were younger, more likely to be female, with a lower household income and rural residence. Distance to GP, nephrologist and general internist, both potential and actual, were even longer for this subcohort of First Nations with diabetes and CKD.

3.2 Proportion of Population Having at Least One Creatinine Measurement, and Frequency of Measurements

The age and sex standardized proportion of the population having at least one creatinine measurement from July 1 to December 31, 2003 in Alberta (six of the nine Health Regions), for First Nations, non-First Nations, and both combined, are shown in **Figure 6**. After standardization, the proportion of the population having at least one creatinine measurement was slightly higher for First Nations (23.56%) compared with non-First Nations (21.67%).

We also calculated the frequency of outpatient serum creatinine measurements over a one year period (July 1, 2003 to June 30, 2004) for our CKD population of First Nations and non-First Nations. First Nations with CKD had more frequent measurements (median 2.5; IQR 1.0 - 5.0) compared with non-First Nations (median 2.0; IQR 1.0 - 4.0).

3.3 Prevalence of Measured CKD

Figure 7 shows the age and sex standardized period prevalence of measured CKD from July 1 to December 31, 2003 in Alberta (six of the nine Health Regions), for First Nations, non-First Nations, and both combined. After age and sex standardization, First Nations had a similar prevalence of measured CKD (4.16 %) as non-First Nations (4.45 %). The age and sex specific prevalence of measured CKD appeared to be higher for First Nations than non-First Nations in the younger age groups (before age 65) and lower at advanced ages (over age 65) for both males and females (**Figure 8**). We further explored this age and prevalence relationship in **Figure 9**. Compared to non-First Nations, First Nations had a slightly higher prevalence of measured CKD (1.71% vs. 1.44%) before age 65, and a lower prevalence (16.16% vs. 19.19%) at age 65 and older. This may be related to the much younger age distribution in First Nations patients with CKD as shown previously in Table 3. Females tended to have a higher prevalence of measured CKD than males, and within each gender category, prevalence increased as age advanced. These prevalence rates likely under-estimate the true prevalence of CKD as they are based only on subjects who had a serum creatinine measurement, and do not reflect a screening of the entire population.

3.4 Ambulatory Care Use

The ambulatory service use (GP visits, nephrologist visits, general internist visits, cardiologist visits, and emergency rooms visits) were examined for the CKD population and the diabetic CKD population.

3.4.1 CKD Population

Ambulatory health care resource use during the study period for First Nations and Non-First Nations with measured CKD are presented in **Table 5**. The majority of the cohort, both First Nations and non-First Nations, had at least one visit to a GP. A higher proportion of First Nations compared to non-First Nations visited GPs for renal (18.9 % vs. 8.0%) and diabetes (40.0% vs. 18.7%) related conditions, while a slightly lower proportion of First Nations had GP visits for vascular related conditions (58.5% vs. 64.5%) (Definitions of renal, diabetes and vascular related conditions are included as **Appendix 3**). There was no difference in the proportion of subjects with measured CKD (defined as a GFR <60 mL/min/1.73 m²) who visited a nephrologist. However, among patients with at least one nephrology visit, First Nations visited more frequently (median number of visits 4 vs. 2, P < 0.001), compared to non-First Nations.

First Nations with measured CKD were also much more likely to have an emergency room visit (75.5% vs. 49.6%), and among those with at least one emergency room visit, the median number of visits was higher (3 visits vs. 2 visits, P < 0.001) compared with Non-First Nations.

3.4.2 Diabetic CKD Population

Ambulatory care use during the study period for First Nations and Non-First Nations with measured CKD and diabetes are presented in **Table 6**. Results are similar to the CKD cohort, in that a higher proportion of First Nations had GP visits for renal and diabetes related conditions, and there was no difference in the proportion with a nephrologist visit. Similar to previous results, First Nations with CKD and diabetes were

much more likely to have an emergency room visit compared to non-First Nations (82.0% vs. 57.8%; $p < 0.001$).

3.5 Likelihood of a Nephrologist Visit for Subjects with $\text{GFR} < 30 \text{ mL/min/1.73m}^2$

Among subjects with a $\text{GFR} < 30 \text{ mL/min/1.73 m}^2$, 24 (17.9%) First Nations and 915 (17.6%) non-First Nations had at least one visit to a nephrologist. When determining the likelihood of a nephrologist visit for these subjects with more severe kidney dysfunction, the crude OR showed no difference between First Nations and non-First Nations (OR 1.02; 95% CI: 0.65 - 1.6). After adjusting for age, sex and diabetes, First Nations were 37% (OR 0.63; 95% CI: 0.40 - 0.99; $p = 0.048$) less likely to have a visit (**Table 7**). The results also suggested that females and subjects of older age were less likely to visit a nephrologist, while subjects with diabetes were 1.2 times more likely to visit a nephrologist. In a further analysis we also included two other variables in the model, namely income (by quintiles) and rural residence (yes/no). When these two variables were separately or jointly added into the model, the association between First Nations status and likelihood of nephrologist visit was no longer statistically significant (OR 0.78; 95% CI: 0.47 - 1.30).

3.6 Hospitalizations for CKD relevant ACSC

Overall, 7.1% ($n = 58$) of First Nations with CKD and 3.1% ($n = 2,190$) of non-First Nations with CKD had at least one hospitalization for a CKD relevant ACSC during the study period (**Table 8**). Among those with at least one hospital admission, the frequency of admissions was similar for the two groups. In a negative binomial regression model the crude rate ratio of hospitalization for a CKD relevant ACSC was 2.90 (95% CI 1.91 - 4.40)

for First Nations compared to non-First Nations with measured CKD. After adjustment for sex, age, diabetes and GFR level (GFR < 30 mL/min/1.73 m² or GFR 30 – 59 mL/min/1.73 m²), First Nations were still over 2.5 times as likely to be hospitalized for a CKD relevant ACSC compared to non-First Nations (Rate ratio 2.59; 95% CI 1.76 - 3.81) (Table 9). Diabetes, lower GFR level, and older age were strong predictors of hospitalization for ACSC among CKD patients (**Table 9**).

We further examined the effect of income and rural residence on hospitalization for CKD relevant ACSC. In this model (**Table 10**) the rate ratio of hospitalization for First Nations compared to non-First Nations was reduced from 2.59 (95% CI 1.76 – 3.81) to 1.80 (1.18 – 2.74), suggesting that rural residence and income level explained some of the difference in risk of hospitalization between the two populations. People living in rural areas had a higher risk for hospital admissions, where approximately half of First Nations resided. Subjects in the highest income quintile were 30% less likely to be hospitalized as compared to people in the lowest income quintile (which included more than half of the First Nations population). We tested effect modification of income and rural location of resident with the main effect of First Nation status by adding the interaction terms in the model. The interaction terms were not significant, suggesting that the association between First Nations status and likelihood of hospitalization for a CKD relevant ACSC did not vary by income and rural location of residence.

DISCUSSION

4.1 Proportion of Population Having at Least One Serum Creatinine Measurement

We found that the proportion of the First Nation population in our study who had at least one serum creatinine measurement was slightly higher than the non-First Nation population (23.56% vs. 21.67%) during the six month study period. Interestingly, among those who had a creatinine measurement, 79.9% of non-First Nations had a reduced GFR level ($\text{GFR} < 90 \text{ mL/min/1.73 m}^2$), compared to only 54.2% of First Nations. This may suggest that more non-First Nations had a creatinine measurement for CKD, while First Nations may obtain creatinine measurements for reasons other than determining or monitoring kidney disease. In addition, we cannot exclude the possibility that First Nations with CKD did not obtain a creatinine measurement and our estimate of CKD prevalence is undoubtedly an underestimate of the true CKD prevalence, in both First Nations and non-First Nations.

Our results regarding the proportion of the population obtaining serum creatinine measurements are similar to that reported by Garg et al (88). Using a similar laboratory based assessment of serum creatinine measurements in Eastern Ontario, the authors reported that 32.1% of adults had at least one serum creatinine measurement over a one year period (September 1, 1999 to September 1 2000). If we were to extend our study period from 6 months to one year we would expect a similar proportion to that reported in the Ontario based study.

4.2 Prevalence of Measured CKD

In our study we found that the crude period prevalence of measured CKD from July 1 to December 31, 2003 was twice as high for non-First Nations compared to First Nations (3.87% vs. 1.77% respectively). However, the age and sex standardized period prevalence of measured CKD was similar for the two groups, at 4.45% for non-First Nations, and 4.16% for First Nations. For both First Nations and non-First Nations, females tended to have higher prevalence of measured CKD than males and within each gender category the prevalence increased as age advanced. Among subjects 65 years of age and older, the age and sex standardized prevalence of measured CKD was higher in non-First Nations (19.19%) compared to First Nations (16.16%).

Other studies have determined the prevalence of measured CKD in the general population, enabling comparison with the results noted in our study. The Canadian based study by Garg et al, using a similar laboratory based assessment, reported that 5.0% of population had a GFR of $< 60 \text{ mL/min/1.73 m}^2$ (88). Although the crude prevalence rate was similar to our study, results should be standardized to the same reference population for purposes of comparison.

We also compared our results with the Third National Health and Nutrition Examination Survey (the NHANES study) conducted in the United States (39). While this comparison can not adjust for potential differences in age and sex distributions between the Canadian and the U.S. populations, the NHANES study provides a representative sample of the U.S. population for examining disease prevalence and trends over time. Of note, the NHANES researchers reported that the prevalence of CKD (GFR 15 to 59 mL/min/1.73 m²) remained stable over the past decade ($4.4 \pm 0.3\%$ in 1988 to 1994 and 3.8

$\pm 0.4\%$ in 1999 to 2000). If we were to exclude the subjects with $\text{GFR} < 15 \text{ ml/min per } 1.73 \text{ m}^2$ from our study, our prevalence estimates would be similar, as only 1.2 % of subjects (combining First Nations and non-First Nations) in the CKD population had $\text{GFR} < 15 \text{ mL/min/1.73 m}^2$. On the other hand, our prevalence rates may under-estimate the true prevalence of CKD in Alberta, as only subjects who had a serum creatinine measurement obtained as an outpatient between July 1 and December 31 2003 were included. Acknowledging this potential limitation, and ignoring the potential difference in age and sex distributions between the two countries, the prevalence of CKD in the U.S. general population appears similar to the Alberta non-First Nations population. The NHANES study also reported a higher prevalence of CKD in woman compared to men, and among subjects 65 years of age and older, which was consistent with our findings (39).

A population based study in Australia estimated that CKD ($\text{GFR} < 60 \text{ mL/min/1.73 m}^2$) was present in 11.2% of study participants (89). As noted by the authors, the higher prevalence of CKD may be due to use of a different method of estimating GFR, namely, the Cockcroft-Gault equation. Similar to our results, the prevalence of CKD ($\text{GFR} < 60 \text{ mL/min/1.73 m}^2$) was greater in women and increased with age.

Although studies of the prevalence of CKD among Aboriginal people are not available to directly compare with our observed prevalence rates, studies have been conducted which demonstrate increased rates of kidney disease among the Aboriginal population in both diabetics and non-diabetics, as evident by urinary albumin excretion rates (36) . The Strong Heart Study (37), a longitudinal population-based study of cardiovascular disease risk factors among American Indians, has shown high rates of abnormal urinary albumin excretion in all Aboriginal communities. A large proportion of the study population (53%) had diabetes, which may account for the increased rates of

albuminuria. However, even among subjects without diabetes, the prevalence of abnormal albuminuria ranged from 10 – 20%. The rate of albuminuria in the non-Aboriginal population is reported to be much lower at $10.1\% \pm 0.7\%$ (39).

Another population-based, cross-sectional survey, the Zuni Kidney Project in New Mexico (38), also showed increased albuminuria excretion rates among the non-diabetic Zuni Indian population. The prevalence of albuminuria among non-diabetics was 10.5% for females and 14.7% for males.

Somewhat surprisingly, we observed a similar prevalence of measured CKD for First Nations and non-First Nations. The proportion of the First Nation population in our study who had a serum creatinine measurement was slightly higher than the non-First Nation population, suggesting that First Nations are just as likely to obtain serum creatinine measurements as non-First Nations. However, whether First Nations people *with CKD* were as likely to obtain serum creatinine measurements as non-First Nations *with CKD* is not possible to determine from our data. Given the higher prevalence of diabetes among the First Nations population, and the association between diabetes and risk of kidney disease, we would have expected a higher prevalence of CKD among the First Nations population. The 2.5 to 4 times higher ESRD rates among Aboriginal people compared to the general of the Canadian population (35), would also indicate a potential increased prevalence of CKD in the First Nation population.

Similar results were reported in the NHANES study (39) when blacks were compared with non-Hispanic whites, with Blacks having a higher rates of ESRD, but a lower prevalence of CKD. The authors suggested three possible explanations for these findings, which may also be relevant for the First Nations population and results reported in our study: first, rates of progression from CKD to ESRD is faster among blacks; second,

competing mortality from cardiovascular disease is higher among non-blacks; and finally, poorer access to quality care among blacks may negatively affect the progression from CKD to ESRD. These possible explanations may also be applicable for the First Nation population in Alberta. However, the possibility that more First Nations with CKD than non-First Nations did not obtain creatinine measurement could also result in a lower prevalence of measured CKD for First Nations in our study. As discussed in the previous section, among those who had a creatinine measurement, 79.9% of non-First Nations had a reduced GFR level, compared to only half of the First Nations population. In summary, it would appear that the prevalence of measured CKD among First Nations in Alberta obtained in our study may be an under-estimate of the true prevalence.

4.3 Pattern of Ambulatory Care Use for Subjects with CKD

The majority of the non-First Nation (95.4%) and First Nation (96.6%) population with CKD had at least one GP visit during the study period (Index date to March 31, 2005). This high likelihood should not be surprising given that a GP visit would have generally been required for the patients to have obtained a requisition to measure a serum creatinine. However, First Nations had approximately twice as many visits to a GP for renal and diabetes related conditions compared to non-First Nations. The pattern of utilization of GP services was similar for the subcohort of subjects with both CKD and diabetes, with a greater proportion of First Nations utilizing GP services for renal and diabetes related conditions. These findings suggest that First Nations with CKD in our study population utilized GP services on a frequent basis. Although the validity of physician claims in defining the indication for the visits is limited, there is no reason to believe that

misclassification would be differential for the First Nation and non-First Nations populations and therefore the differences reported should be valid.

The proportion of the First Nations population with at least one nephrology visit was similar to the non-First Nations population for the overall cohort, as well as the subgroup with both CKD and diabetes. However, nephrologist visits for subjects with a $\text{GFR} < 30 \text{ mL/min/1.73 m}^2$ is more clinically relevant given that published guidelines suggest referral to a Nephrologist for patients with a $\text{GFR} < 30 \text{ mL/min/1.73 m}^2$. These findings are discussed in the following section.

First Nations were less likely to visit a cardiologist in our study, which may be related to the fact that a greater proportion of First Nations visited a GP for vascular diseases. In contrast, a greater proportion of First Nations than non-First Nations had a visit to a general internist. This finding may be related to the fact that general internists are more widely located throughout the province than cardiologists, and thus may be more accessible for the primarily rural dwelling First Nations population.

First Nations with CKD also utilized emergency rooms much more frequently, with over 75% having at least one emergency room visit in the study period, compared to approximately 50% of the non-First Nations population with CKD. Whether this is a reflection of an overall poorer health status, or lack of access to a regular GP or specialist physician, is not possible to determine from our study.

The pattern of ambulatory health services use that we reported for First Nations with CKD in Alberta is consistent with several Canadian studies of health services use among Aboriginal people for other medical conditions. The First Nations Health Services Study (13) conducted by Alberta Health and Wellness based on administrative data sources compared the use of health care services in the year 2000 among First Nations people and

matched non-First Nations controls. The study found that except for neoplasms, the numbers and rate ratios of ambulatory services for all other disease conditions were higher among First Nations. Among diabetic patients, First Nations were 2.6 times more likely than matched controls to go to a GP's office, and they were 4 times more likely to have an emergency room visit.

A Manitoba population based study of health services use among First Nations (59), similarly based on administrative data but not restricted to subjects with CKD, also showed that First Nations were 1.3 times more likely to have an outpatient physician visit (regardless of physician types) than other Manitobans.

4.4 Likelihood of a Nephrologist Visit for Subjects with GFR < 30 mL/min/1.73 m²

Despite guidelines that suggest subjects with a GFR < 30 mL/min/1.73 m² should be referred to a nephrologist, the results of our study suggest that First Nations were less likely to have a nephrologist visit compared to non-First Nations. After adjusting for age, sex and diabetes, First Nations were 37% less likely to have a nephrologist visit compared to non-First Nations (OR 0.63; 95% CI 0.40 – 0.99; p=0.48). This finding must be interpreted with caution, not only because of the minimal statistically significant association, but also because First Nations who lived in the rural areas (approximately 50%) may have consulted general internists for renal related problems. The lack of a strong statistically significant finding may also be related to the limited number of First Nations who had a nephrologist visit, and limited power.

The final results shown in **Table 7** did not include adjustment for income and rural residence. We agreed with the argument by the well respected researcher on Aboriginal health, T Kue Young, that “statistically ‘controlling’ for socioeconomic status and

geographic isolation, while feasible, may not be advisable, as such factors are central to the Aboriginal experience in many regions, and removing them takes away the most powerful explanatory variable” (90). Inclusion of income and rural residence variables in our final model may result in over-adjustment, particularly since the majority of the First Nations population with CKD were from the lowest income quartile, and lived in a rural location.

In general, ethnic minorities report greater difficulties in obtaining referral and accessing specialist physician care (52). Canadian studies indicate that First Nations are less likely to see a specialist compared to non-First Nations. A 2002 opinion poll of the National Aboriginal Health Organization suggested that less than half of the Aboriginal population surveyed reported easy access to specialist services (58). The Manitoba study mentioned in the previous section using administrative data showed that the specialist visit rates (both initial consult and follow-up) were lower (0.895 vs. 1.284 per person; $p < 0.05$) among First Nations as compared with other Manitobans (59).

There are several possible reasons why First Nations people with $\text{GFR} < 30\text{mL/min/1.73 m}^2$ were less likely to see a nephrologist. It is possible that there were unmeasured differences in severity of disease (i.e. associated comorbid conditions, etc) that our study did not account for, although it seems unlikely given the findings of other studies which would suggest that comorbidity would be higher among First Nations patients with CKD. Other explanations may be that First Nations with CKD did not have a consistent source of care from the same GP and thus may experience a lower likelihood of referral to a nephrologist, as specialist referral may be increased with regular GP care. Although our results suggest that First Nations patients are as likely as non-First Nations to visit GPs, it is possible that more visits are for assessment and treatment of acute conditions, rather than preventative care for conditions like CKD. It is also possible that potential referral biases

exist towards First Nations patients. Finally, since specialists are often located in large urban centers, e.g., nephrologists are located in only 5 urban centers in Alberta, First Nations (about half of them living in the rural areas) may not be able to travel the distance to see a specialist, even if they were referred.

4.5 Quality of Access to Ambulatory Care

Not only did a higher proportion of First Nations with CKD utilize GP services for renal and diabetes related conditions compared to non-First Nations, they were also twice as likely to have a hospitalization for a CKD relevant ACSC. This finding persisted after adjustment for age, gender, kidney disease severity and diabetes. As discussed in Section 4.4 above, our final model did not include adjustment for income and rural residence because of concerns regarding over adjustment, although we did include these variables in **Table 10** for discussion purposes only.

Despite universal access to care that is available in the Canadian health care system, these results suggest that access to, and appropriate management of, CKD care in an ambulatory care setting may be more limited for First Nations compared to non-First Nations. Although First Nations tended to have more frequent ambulatory care visits, access to nephrologists was limited for these patients with CKD, who may benefit the most from this care.

Our use of ACSC as a measure of appropriate access and outpatient management was based on previous studies reporting a link between health care access and ACSC hospitalization rates (91;92). These studies reported that self-rated access to care was inversely and independently associated with hospitalization rate for ACSC even after controlling for demographics, income, prevalence of the conditions, health care seeking

behavior, and physician practice style (91;92). Several other studies have described the existence of a similar relationship (71;74;93-95), thus supporting the validity of the use of hospitalizations for ACSC as a measure of access to quality health care. Importantly, previous studies based on ACSC were limited in that they often aggregated ACSC from different unrelated disease categories into one single summary measure, and therefore were unable to account for disease severity. This is important because disease severity may account for some differences in hospitalization rates across groups. In fact, very few studies on ACSC have controlled for disease severity (68). A strength of our study, which included estimates of kidney function at the individual level, was the ability to adjust for underlying disease severity based on the estimated GFR in assessing the likelihood of hospitalization for a CKD relevant ACSC.

The results of an increased rate of hospitalizations for CKD relevant ACSC for First Nations with CKD in our study are consistent with a population based study in Ontario (70). This study, which included more than 80% of Ontario's Aboriginal communities, examined a list of different ACSC and reported ACSC hospitalization rates twice as high for the Aboriginal population relative to the general population. After limiting their analyses to the rural population (i.e., community size was less than 10,000) and low socioeconomic status population, the Aboriginal population still had slightly higher rates of potentially preventable hospitalizations (RR = 1.50; and RR = 1.14, respectively). A U.S. study of 37 counties in California also found the age and sex adjusted ratio of avoidable hospitalizations were 136% higher (RR 2.36, CI 1.52 – 3.29) for men and 106% (RR 2.06, CI 1.32 – 3.50) higher for women for American Indians compared to non-American Indians (96).

4.6 Understanding the Gap

Although our findings suggest that First Nations people have reasonable access to GPs, as reflected by a greater proportion of them having a GP visit, the lower likelihood of a nephrologist visit for First Nations with severe CKD, and higher hospitalization rates for CKD relevant ACSC, would suggest that factors other than simple access to GPs is influencing the quality of their CKD care. To aid in interpreting our study results, we will discuss the findings in the context of the Anderson and Aday model, as well as the factors of ethnicity. The findings will be discussed as they relate to patient, health care system and provider level variables.

Patient level variables:

In our study we were able to adjust for some patient level factors such as predisposing factors (i.e., baseline demographic characteristics and ethnicity), enabling factors (i.e., income level) and needs factors (i.e., the severity of CKD and diabetes comorbidity). Although we did have data regarding income, we chose not to include this in the final model due to concerns of over-adjustment. Although not included in our final model, when income level was added it did explain some of the difference in the hospitalization rates across groups (**Table 10**). This is consistent with the work by Shah et al (70), who also reported a link between high hospitalization rates for ACSC and low socioeconomic status among Aboriginal people. The relationship between low socioeconomic status and increased risk of hospitalization for ACSC has been reported in other settings as well (68;70;72;73).

As our data did not allow us to explore the social factors surrounding First Nation origin that could affect health care use, we instead must rely on the theories of ethnicity, as

discussed in the background section, to attempt to understand other factors that may contribute to the higher GP utilization rates, lower likelihood of a nephrologist visit and higher ACSC hospitalization rates for First Nations compared to non-First Nations with CKD.

Loss of traditional Aboriginal culture and way of life over time are felt by the Aboriginal elders in particular as being important factors contributing to the poorer overall health status of the Aboriginal population. It is a strong belief of Aboriginal Elders that First Nations people had greater longevity and health in the past, compared to now. They believe that a return to traditional lifestyles is important as a way of improving health. We may understand their values and beliefs through the words of the elders, which suggest negative feelings and possible mistrust with Western Medicine rather than traditional medicine:

“The Aboriginal community has been hit very hard. Before those things happened, we had a very strong community. Our culture beliefs were very strong ...We were very strong. But what is important is what the elders told us and that is to keep our mind clear to be strong, and to keep our body in good shape. Respect it. Look after it. Keep your spirituality alive. Look after your spirit each day. Most of these things are forgotten. Drugs are used. Now our people have developed certain disorders.” (Isabel Auger, February 19, 2002) (13).

These and related comments would suggest that First Nations with prior negative experiences with the health care system may develop mistrust with health care professionals within the current health care system. Although we found that First Nations with CKD did attend GP visits, we were unable to determine the outcome of the visits, or whether they followed through with the treatment recommendations. It is possible that

mistrust of the health care system, lack of understanding regarding the severity of their illness, or inability to undertake the treatment recommendations because of personal limitations, resulted in them having an increased rate of hospitalizations for ACSC.

Health care system level:

From the system level we considered the influence of rural location of residence and likelihood of specialist referral. As discussed previously, in modeling the hospitalization rates for ACSC rural location of residence was considered a component of ethnicity (First Nations status) rather than an independent predictor of hospitalization to avoid over-adjustment. However, when added to the model, we did find that people living in rural areas had a higher rate of hospitalization for ACSC. The socioeconomic and geographic barriers which are largely present among First Nations with CKD may result in a delay in their seeking care for CKD, for which early detection and treatment may yield an improved prognosis. The fact that most First Nations lived in the rural area, combined with their lower income level may also be barriers for them to obtain recommended medications, thus negatively affecting their health outcomes.

We also found that First Nations with more severe CKD were less likely to visit a nephrologist for specialized care than non-First Nations, which may also impact their disease progression, and increase their likelihood of a hospitalization for ACSC. Having access to nephrologists for management of CKD is recommended for patients with $GFR < 30 \text{ mL/min/1.73 m}^2$ to slow progression of their CKD, to manage comorbid conditions effectively and thereby to avoid potential hospitalizations.

We were unable to measure other important system level variables which may explain the increased hospitalization rates for ACSC among First Nations. The current health system may not provide sufficient services to help First Nations and the members of

the health care profession overcome linguistic, cultural and knowledge barriers when seeking care. Potential knowledge barriers on behalf of the Aboriginal population regarding modern medicine, and their chronic condition in particular, may influence the treatment received as well as management of their chronic condition. These barriers may affect medical decision making by physicians under time pressure, and lack of knowledge of the disease condition and severity by First Nations may delay their seeking or adhering to treatment.

Provider level variables:

Although we were not able to assess the provider related factors that may affect First Nations' care seeking behavior within the context of this study, the possibility that cultural bias and perceptions on behalf of the health care provider toward the First Nations population should also be considered (97).

In summary, we were unable to determine whether (or how) ethnicity per se resulted in the observed gap between more GP visits and higher hospitalization rates for ACSC among First Nations people with CKD. Future research is needed to clarify the reasons for this discrepancy and the link between ethnicity and differential health outcomes in this area. However, a better understanding of these factors would not change our results per se, as the effect of these factors on hospitalization rates between First Nations and non-First Nations were embedded in the 'First Nations status' variable.

STUDY LIMITATIONS

The results of our study should be interpreted in context of the study limitations. Firstly, by using out-patient serum creatinine measurements to identify our study cohort we included a select group of CKD patients who had access to the health care system and had already obtained a serum creatinine measurement. This would result in a possible selection bias if the likelihood of having a serum creatinine measurement among subjects with CKD varied by racial status. The fact that the proportion of First Nations and non-First Nations who had a serum creatinine measurement was similar is reassuring, however we were unable to determine if subjects with CKD were more or less likely to have their serum creatinine measured, and whether this varied by racial group. Our prevalence estimates of measured CKD for the non-First Nations population were similar to those reported in the US using a population-based screening study. Assuming a similar prevalence of CKD in Alberta and the US, this would suggest that the majority of non-First Nations population with CKD were having serum creatinine measurements. Whether the same is true for the First Nations population with CKD is not possible to determine from this study, and would require a population based screening study.

A second limitation is the lack of calibration of our creatinine measurements to the Cleveland Clinic where the MDRD GFR equation was derived, which may influence the prevalence estimates (98). However, the similarity of our prevalence estimates to that of the Ontario study by Garg et al (88) , which also used a laboratory based method of screening, suggests our results are valid.

A second limitation is the inability to distinguish prevalent from incident cases of CKD, as laboratory data of prior creatinine measurements is not uniformly available from

the computerized data sources. However, given the chronic nature of this condition it is likely that most cases will represent prevalent CKD. The similar CKD prevalence estimates from the US supports that assumption.

The lack of a gold standard to measure access to care is another study limitation. We did, however, utilize a variety of factors to obtain a proxy measure of access including ambulatory health care resource use, likelihood of nephrology visits for patients with severe kidney disease, and use of a previously developed measure, namely hospitalization for ACSC, which has been shown to be a valid measure of access to outpatient care. Taken together these measures provide a reasonable assessment of access to care.

Our study was further limited by the use of administrative data sources. These administrative sources contain limited data, and did not permit us to assess potential health care system and provider-related variables which may partly explain the difference in health services utilization and likelihood of hospitalization for ACSC evident in our results. Further, the data sources utilized in our study did not contain information on medication use for the First Nations population. This information would be useful in future research to characterize adequacy of CKD care. Finally, we were not able to identify Métis and Inuit people from the non-First Nations group, which may result in misclassification of some Aboriginal patients with CKD in the non-First Nations group. This potential misclassification would likely result in an under-estimate of effect demonstrated in our study. Although it can be argued that this would also limit the generalizability of our results to Aboriginal people of First Nations status, given that the majority (54.4%) of the Aboriginal population in Alberta is comprised of First Nations, these results would be relevant for the majority of the Aboriginal population in Alberta. Administrative data was also used to determine the indication for the GP and specialist visits. Although there is

potential misclassification of these indications, it is unlikely to occur differentially for First Nations and non-First Nations, and therefore would result in a bias of the effect towards the null.

CONCLUSION

In summary, we found that First Nations with CKD utilized GP services as frequently as non-First Nations, however there was a trend towards lower utilization of specialist services in general, and First Nations were twice as likely to be admitted to hospital for a condition that, if managed appropriately in the out-patient setting, may have prevented the need for a hospital admission. First Nations with more severe CKD were also less likely to visit a nephrologist for specialized care than non-First Nations. These results suggest that there may be potential inequities in either access to health care for First Nations with CKD, management of CKD and associated health conditions by the health care system or the patients' themselves, or an overall poorer health status of First Nations with CKD.

Regardless of the exact cause, the issues surrounding reduced access to specialist and the increased risk of hospitalization for ACSC for First Nations people is not only clinically relevant, but is also socially and politically important, as without adequate treatment CKD can progress to ESRD requiring dialysis. Further research to determine the etiology for the increased risk of hospitalization for ACSC is warranted. Moreover, the development of health care initiatives that are acceptable to First Nations communities and will improve the delivery of health care for First Nations people with CKD is required.

SIGNIFICANCE AND FUTURE RESEARCH

To the best of our knowledge, this study is the first to assess the burden of CKD among First Nations people in Canada. This study is also one of the first to address the issue of access and potential barriers to health care among First Nations people with CKD. A particular strength of this study is the ability to merge computerized laboratory data with administrative data, enabling adjustment for the severity of CKD at an individual level.

The results from this study are also informative in guiding us to plan studies to further investigate the cause of the higher ESRD rates that have been noted among First Nations compared to non-First Nations people, despite the similar prevalence of CKD noted in our study. This future research will focus on four possible explanations for the higher observed rates of ESRD in First Nations people.

First, we will investigate whether the prevalence of measured CKD that we noted was an underestimate of the true prevalence of CKD for First Nations people (i.e., First Nations subjects with CKD were less likely to obtain a serum creatinine measurement) by determining the proportion of patients with ESRD that had a previous serum creatinine measurement, for both First Nations and non-First Nations people. If the prevalence of unmeasured CKD is in fact higher in First Nations people, then we would expect that more of the First Nations people with new ESRD would be presenting without prior measurement of serum creatinine (i.e. unmeasured/unknown CKD).

Second, we will assess and compare rates of progression of CKD among First Nations and non-First Nations, to determine if more rapid progression of CKD may account for the higher ESRD rates among First Nations. Third, we will determine whether competing mortality, with higher mortality rates among non-First Nations with CKD

compared to First Nations with CKD, may explain the higher ESRD rates for First Nations (i.e. survivorship bias). Finally, we will use prescription drug data to determine if suboptimal management of CKD for First Nations compared to non-First Nations people may also be contributing to the higher rates of ESRD among First Nations people.

The insights from this study may also serve as a basis upon which health care program changes for CKD management for First Nations people can be made. For example, programs that focus on cross-cultural education may assist health providers to overcome cultural barriers when delivering CKD care. Moreover, programs that support the recruitment and/or training of more Aboriginal physicians, who understand the language and needs of their own people could be one of the most effective ways of improving the quality of care for Aboriginal people. At a local level program changes to enhance availability of nephrology and specialized CKD care to First Nations communities may also be important.

The study also demonstrated the importance of including data on culture related variables, e.g., the values and beliefs of Aboriginal people, in understanding the barriers to health care for First Nations people with CKD.

Table 1. CKD Relevant Ambulatory Care Sensitive Conditions

Condition	ICD-9	ICD-10
Diabetes with ketoacidosis	250.1	E11.10, E10.10, E11.11, E10.11
Diabetes with hyperosmolarity	250.2	E11.00, E10.00, E11.01, E10.01
Volume overload	276.6	E87.7 E87.8, E97.0
Hyperkalaemia	276.7	E87.5
Malignant hypertension	401.0	I10.
Heart disease due to malignant hypertension	402.0	I11.9, I11.0
Kidney disease due to hypertension	403.0	I12.9, I12.0
Malignant hypertension heart and renal disease	404.0	I13.9, I13.0, I13.1, I13.2
Malignant secondary hypertension	405.0	I15.0, I15.1, I15.8
Congestive heart failure	428	I50.9

Table 2. Baseline Characteristics of Study Subjects (N = 380,879)

Characteristic	Non-First Nation (n = 372,341)	First Nation (n = 8538)	P-value *
Age, yr, median (IQR)	54 (42 , 68)	43 (33 , 55)	<.0001
Female, (%)	213,537 (57.4)	5131 (60.1)	<.0001
GFR mL/min/1.73 m ² , median (IQR)	77.9 (65.6, 91.4)	87.8 (74.1, 103.3)	<.0001
GFR mL/min/1.73 m ² stage, (%)			<.0001
≥ 90	74815 (20.1)	3909 (45.8)	
60 - 89	227745 (61.2)	3809 (44.6)	
30 - 59	64336 (17.3)	683 (8.0)	
15 - 29	4657 (1.3)	92 (1.1)	
< 15	788 (0.2)	45 (0.5)	
Diabetes mellitus, (%)	47728 (12.8)	1823 (21.4)	<.0001
Household income level, (%)			<.0001
1st quintile (lowest)	68440 (19.1)	4060 (53.2)	
2nd quintile	70741 (19.7)	1507 (19.7)	
3rd quintile	72853 (20.3)	944 (12.4)	
4th quintile	70918 (19.8)	621 (8.1)	
5th quintile (highest)	75991 (21.2)	499 (6.5)	
Rural residence (%)	41897 (11.3)	3530 (41.4)	<.0001
Distance to GP, km, median (IQR)	4.8 (2.0, 10.8)	11.6 (2.3, 47.9)	<.0001
Distance to nephrologist, km, median (IQR)			
nearest nephrologist	10.2 (6.1, 17.4)	32.8 (7.5, 79.6)	<.0001
most frequently visited nephrologist **	9.6 (5.7, 14.0))	49.4 (10.8, 86.4)	<.0001
Distance to general internist, km, median (IQR)			
nearest general internist	3.1 (1.6, 7.3)	10.0 (2.0, 57.1)	<.0001
most frequently visited general internist ***	7.8 (3.9, 14.4)	16.9 (5.2, 88.4)	<.0001

* rank-sum test was performed for comparing two medians

Chi-square test was used when comparing proportions

** n = 3739 for non-First Nations and n = 57 for First Nations

*** n = 116948 for non-First Nations and n = 2379 for First Nations

Table 3. Baseline Characteristics of CKD Population (N = 70,601)

Characteristic	Non-First Nation (n = 69,781)	First Nation (n = 820)	P-value *
Age, yr, median (IQR)	61 (72, 80)	60 (51, 70)	<.0001
Female, (%)	43959 (63.0)	511 (62.3)	N.S.
GFR mL/min/1.73 m ² , median (IQR)	51.2 (42.6, 56.3)	48.7 (36.7, 55.7)	<.0001
GFR mL/min/1.73 m ² stage, (%)			<.0001
30 – 59	64336 (92.2)	683 (83.3)	
15 – 29	4657 (6.7)	92 (11.2)	
< 15	788 (1.1)	45 (5.5)	
Diabetes mellitus, (%)	15016 (21.5)	373 (45.5)	<.0001
Household income, (%)			<.0001
1st quintile (lowest)	13719 (20.5)	402 (54.7)	
2nd quintile	13828 (20.6)	141 (19.2)	
3rd quintile	13981 (20.9)	83 (11.3)	
4th quintile	12175 (18.2)	57 (7.8)	
5th quintile (highest)	13338 (19.9)	52 (7.1)	
Rural residence, (%)	8650 (12.4)	385 (47.0)	<.0001
Distance to GP, km, median (IQR)	4.2 (1.8, 9.5)	11.7 (2.0, 46.4)	<.0001
Distance to nephrologist, km, median (IQR)			
nearest nephrologist	9.5 (5.6, 16.9)	46.0 (8.7, 91.4)	<.0001
most frequently visited nephrologist **	9.6 (5.7, 14.0)	49.5 (11.0, 93.9)	<.0001
Distance to general internist, km, median (IQR)			
nearest general internist	2.7 (1.3, 7.1)	21.0 (2.5, 62.9)	<.0001
most frequently visited general internist ***	7.3 (3.6, 13.8)	32.6 (6.9, 131.5)	<.0001

* rank-sum test was performed for comparing two medians

Chi-square test was used when comparing proportions

** n = 2675 for non-First Nations and n = 39 for First Nations

*** n = 29534 for non-First Nations and n = 409 for First Nations

Table 4. Baseline Characteristics of CKD Population with Diabetes (N = 15,389)

Characteristic	Non-First Nation (n = 15016)	First Nation (n = 373)	P-value *
Age, yr, median (IQR)	72 (64 , 79)	62 (55 , 71)	<.0001
Female, (%)	8068 (53.7)	235 (63.0)	<.0001
GFR mL/min/1.73 m ² , median (IQR)	48.3 (38.2, 54.8)	44.4 (29.7, 54.4)	<.0001
GFR mL/min/1.73 m ² stage, (%)			<.0001
30 – 59	13107 (87.3)	279 (74.8)	
15 – 29	1641 (10.9)	60 (16.1)	
< 15	268 (1.8)	34 (9.1)	
Household income level, (%)			<.0001
1st quintile (lowest)	3425 (23.7)	216 (63.9)	
2nd quintile	3281 (22.7)	58 (17.2)	
3rd quintile	3004 (20.8)	25 (7.4)	
4th quintile	2440 (16.9)	20 (5.9)	
5th quintile (highest)	2295 (15.9)	19 (5.6)	
Rural residence (%)	1989 (13.3)	193 (51.7)	<.0001
Distance to GP, km, median (IQR)	4.2 (1.7, 9.5)	13.0 (1.3, 44.8)	<.0001
Distance to nephrologist, km, median (IQR)			
nearest nephrologist	9.6 (5.7, 16.8)	46.8 (9.1, 79.6)	<.0001
most frequently visited nephrologist **	10.2 (6.0, 14.2))	62.0 (15.3, 101.3)	<.0001
Distance to general internist, km, median (IQR)			
nearest general internist	2.7 (1.4, 6.8)	32.2 (2.6, 62.9)	<.0001
most frequently visited general internist ***	7.5 (3.7, 13.9)	32.8 (7.9, 78.6)	<.0001

* rank-sum test was performed for comparing two medians

Chi-square test was used when comparing proportions

** n = 1015 for non-First Nations and n = 26 for First Nations

*** n = 8197 for non-First Nations and n = 217 for First Nations

Table 5. Health Care Resource Use by CKD Population (N = 70,601)

	Non-First Nation (n = 69,781)	First Nation (n = 820)	P-Value *
Physician visits			
GP visits for any conditions	66556 (95.4)	792 (96.6)	N.S.
GP visits for renal related conditions			
number (%) of patients	5564 (8.0)	155 (18.9)	<.0001
Median number of visits among patients with at least one visit	1 (1 , 2)	1(1 , 2)	0.036
GP visits for diabetes related conditions			
number (%) of patients	13065 (18.7)	327 (40.0)	<.0001
Median number of visits among patients with at least one visit	3 (1 , 5)	4 (2 , 7)	<.0001
GP visits for vascular related			
number (%) of patients	45024(64.5)	480 (58.5)	0.000
Median number of visits among patients with at least one visit	3 (2 , 6)	2 (1 , 5)	<.0001
Nephrologist visits			
number (%) of patients	2676 (3.8)	39 (4.8)	N.S.
Median number of visits among patients with at least one visit	2 (1 , 4)	4 (2 , 43)	0.001
Cardiologist visits			
number (%) of patients	15166 (21.7)	135 (16.5)	0.000
Median number of visits among patients with at least one visit	2 (1 , 3)	2 (1 , 2)	N.S.
General Internist visits			
number (%) of patients	29540 (42.3)	409 (50.0)	<.0001
Median number of visits among patients with at least one visit	2 (1 , 4)	2 (1 , 5)	0.000
Emergency room visits			
number (%) of patients	34623 (49.6)	619 (75.5)	<.0001
Median number of visits among patients with at least one visit	2 (1 , 3)	3 (2 , 7)	<.0001

* rank-sum test was performed for comparing two median;
Chi-square test was used when comparing proportions

Table 6. Health Care Resource Use by CKD Population with Diabetes (N = 15,389)

	Non-First Nation (n = 15016)	First Nation (n = 373)	P-Value *
Physician visits			
GP visits for any conditions	14455 (96.3)	366 (98.1)	N.S.
GP visits for renal related conditions			
number (%) of patients	1662 (11.1)	91 (24.4)	<.0001
Median number of visits among patients with at least one visit	1 (1 , 2)	1(1 , 2)	N.S.
GP visits for diabetes related conditions			
number (%) of patients	11392 (75.9)	309 (82.8)	<.0002
Median number of visits among patients with at least one visit	3 (2 , 6)	4 (2 , 7)	<.0001
GP visits for vascular related			
number (%) of patients	10657(71.0)	254 (68.1)	N.S.
Median number of visits among patients with at least one visit	3 (2 , 6)	2 (1 , 5)	0.005
Nephrologist visits			
number (%) of patients	1015 (6.8)	26 (7.0)	N.S.
Median number of visits among patients with at least one visit	2 (1 , 5)	5 (2 , 53)	0.005
Cardiologist visits			
number (%) of patients	3708 (24.7)	73 (19.6)	0.023
Median number of visits among patients with at least one visit	2 (2 , 6)	3 (1 , 5)	N.S.
General Internist visits			
number (%) of patients	8197 (54.6)	217 (58.2)	N.S.
Median number of visits among patients with at least one visit	3 (1 , 5)	3 (1 , 7)	N.S.
Emergency room visits			
number (%) of patients	8684 (57.8)	306 (82.0)	<.0001
Median number of visits among patients with at least one visit	2 (1 , 4)	4 (2 , 8)	<.0001

* rank-sum test was performed for comparing two median;
Chi-square test was used when comparing proportions

Table 7. Likelihood of a Nephrologist Visit for Patients with GFR < 30 mL/min/1.73 m²

Variables	OR	95% Confidence Limits		P Value
First Nations vs. Non-First Nations	0.63	0.40	0.99	0.048
Age 62 - 74 *	0.65	0.54	0.79	<.0001
Age 75 - 81 *	0.44	0.35	0.55	<.0001
Age > 81	0.24	0.19	0.30	<.0001
Female	0.64	0.55	0.73	<.0001
Diabetes	1.20	1.03	1.40	0.017

* Reference group is aged 20 – 61

Table 8. Proportion of Subjects with Hospitalizations for CKD Relevant ACSC, and Frequency of Admissions

Hospital admissions	Non-FNs	FNs	P-value
Number (%) of patients with at least one admission	2190(3.1)	58 (7.1)	<.0001
Median(IQR) # of admissions among those admitted	1 (1 , 1)	1 (1 , 2)	0.012

Table 9. Rate Ratio of Hospitalization for CKD Relevant ACSC

Variables	RR	95% Confidence Limits		P Value
First Nations vs. Non-First Nations	2.59	1.76	3.81	<.0001
Age 62 - 74 *	1.52	1.30	1.78	<.0001
Age 75 - 81 *	2.77	2.35	3.26	<.0001
Age > 81 *	4.97	4.26	5.81	<.0001
Female	0.66	0.60	0.74	<.0001
GFR < 30 vs. GFR (30 - 59)	4.59	3.97	5.30	<.0001
Diabetes	3.24	2.90	3.61	<.0001

* reference group: age 20 - 61

Table 10. Rate Ratio of Hospitalization for CKD Relevant ACSC (including residence and income)

Variables	RR	95% Confidence Limits		P Value
First Nations vs. Non-First Nations	1.80	1.18	2.74	0.006
Female vs. Male	0.67	0.60	0.75	<.0001
Age (62 - 74) vs. Age (20 - 61)	1.47	1.25	1.72	<.0001
Age (75 -81) vs. Age (20 - 61)	2.67	2.25	3.16	<.0001
Age > 81 vs. Age (20 - 61)	4.98	4.25	5.84	<.0001
Diabetes (Yes vs. No)	3.25	2.91	3.64	<.0001
GFR < 30 vs. GFR (30 - 59)	4.47	3.86	5.20	<.0001
Rural vs. Non-Rural	2.01	1.75	2.32	<.0001
Income (2nd Quintile vs. 1st Quintile)	0.90	0.77	1.05	0.175
Income (3rd Quintile vs. 1st Quintile)	0.75	0.64	0.88	0.000
Income (4th Quintile vs. 1st Quintile)	0.77	0.66	0.91	0.002
Income (5th Quintile vs. 1st Quintile)	0.70	0.59	0.82	<.0001

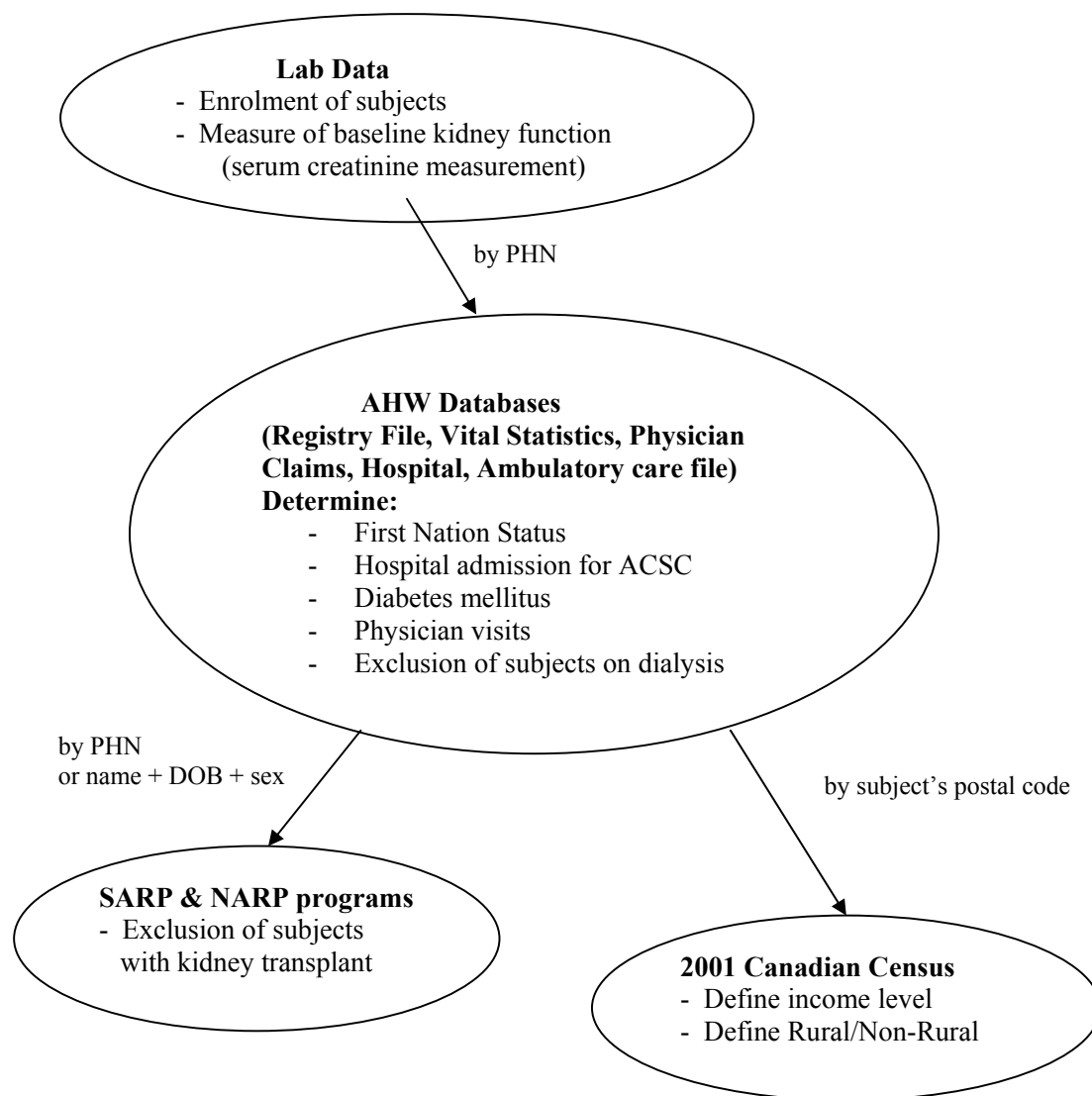
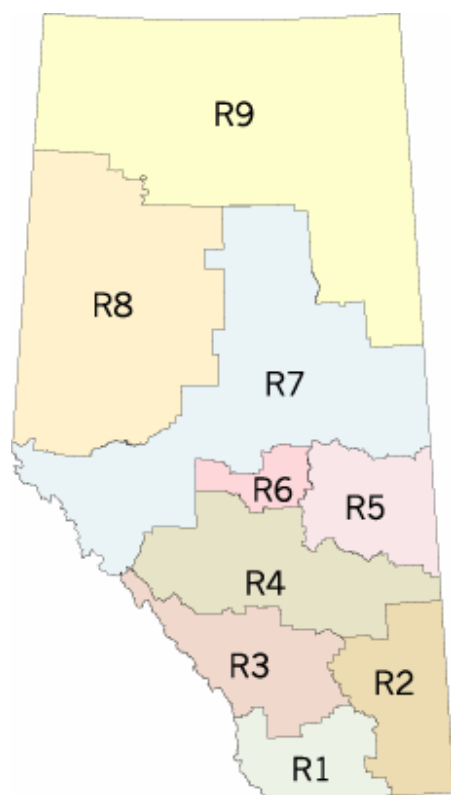
Figure 1: Data Sources and Linkage

Figure 2. Map of Regional Health Authorities in Alberta

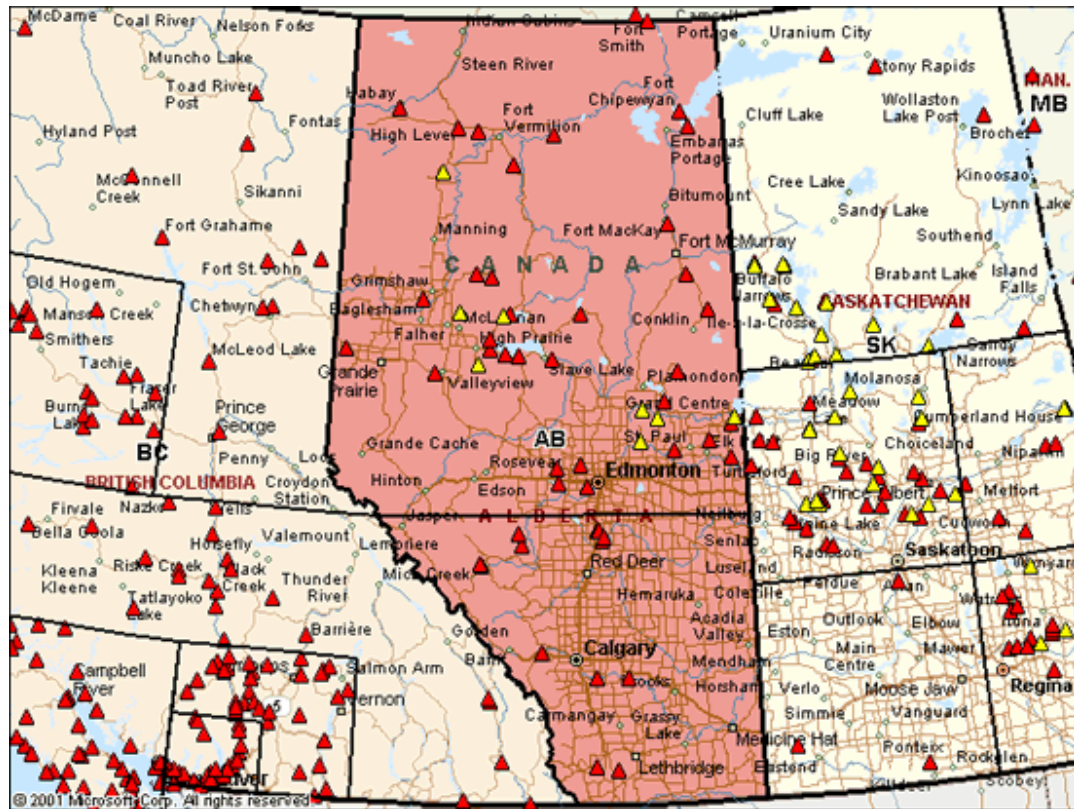


Names of Regional Health Authorities:

1. Chinook Regional Health Authority
2. Palliser Health Region
3. Calgary Health Region
4. * David Thompson Regional Health Authority
5. * East Central Health
6. Capital Health
7. * Aspen Regional Health Authority
8. Peace Country Health
9. Northern Lights Health Region

* Health Regions not included in current study

Figure 3. Map of First Nations Communities in Alberta



- ▲ First Nation
- △ Inuit
- ▲ Métis

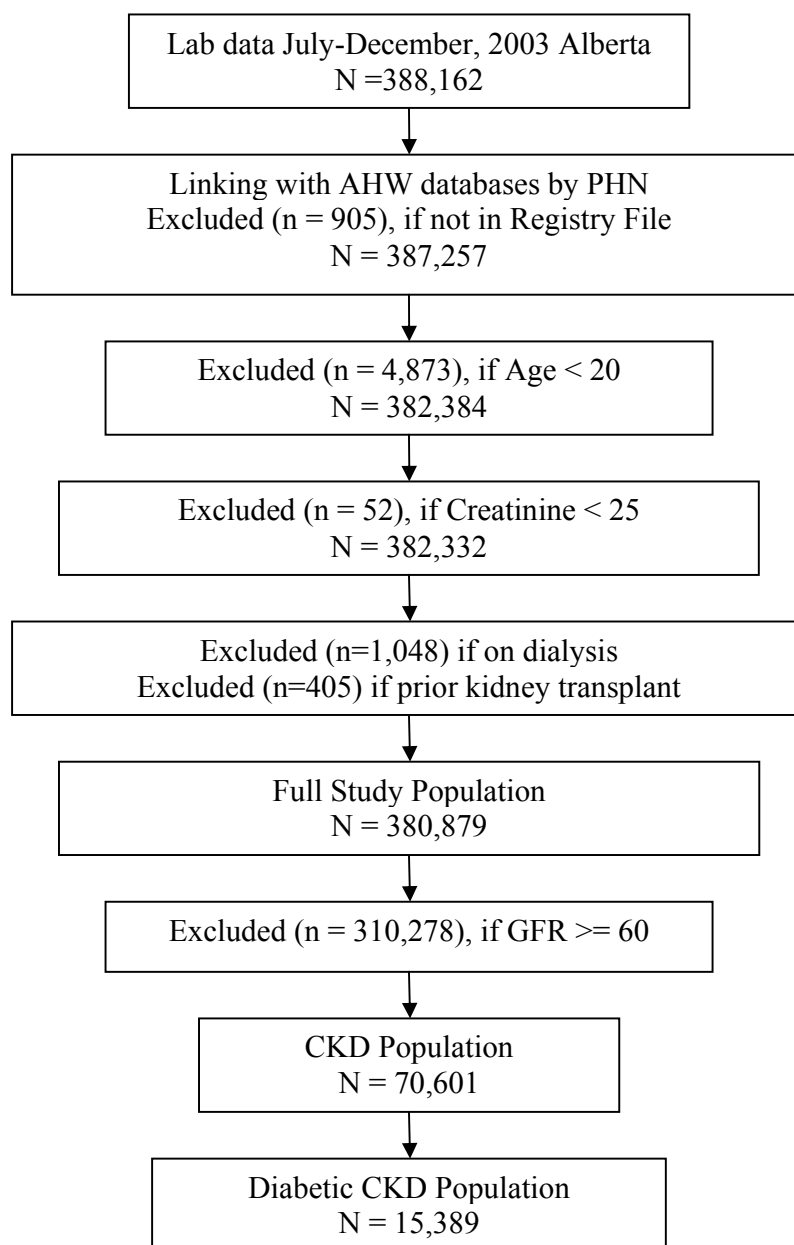
Figure 4. Study Population

Figure 5. Geographic Distribution of CKD Patients within Each Health Region By First Nation Status

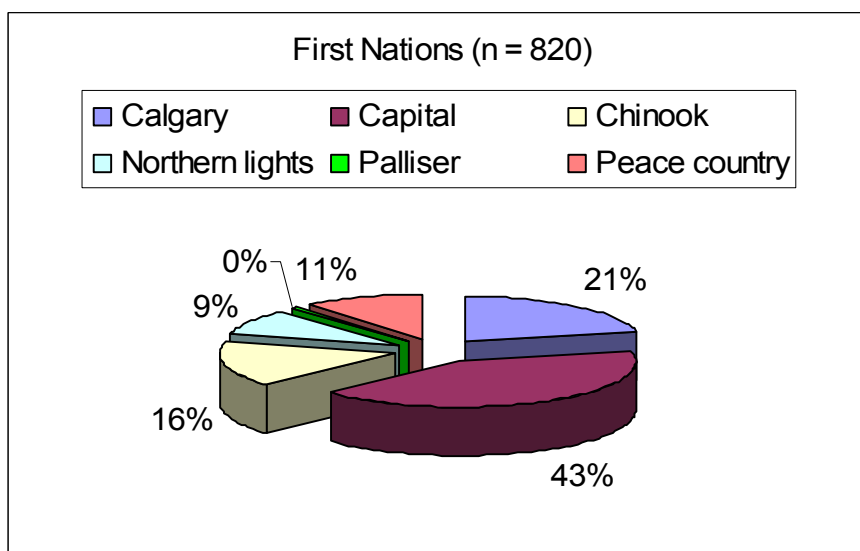
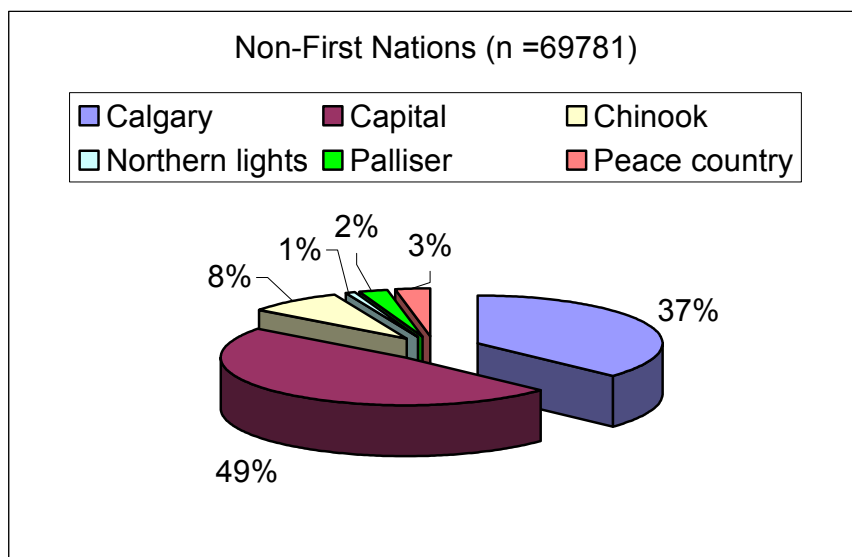


Figure 6. Age and Sex Standardized Proportion of Population having at least One Creatinine Measurement in Alberta, July to December 2003, by First Nations Status

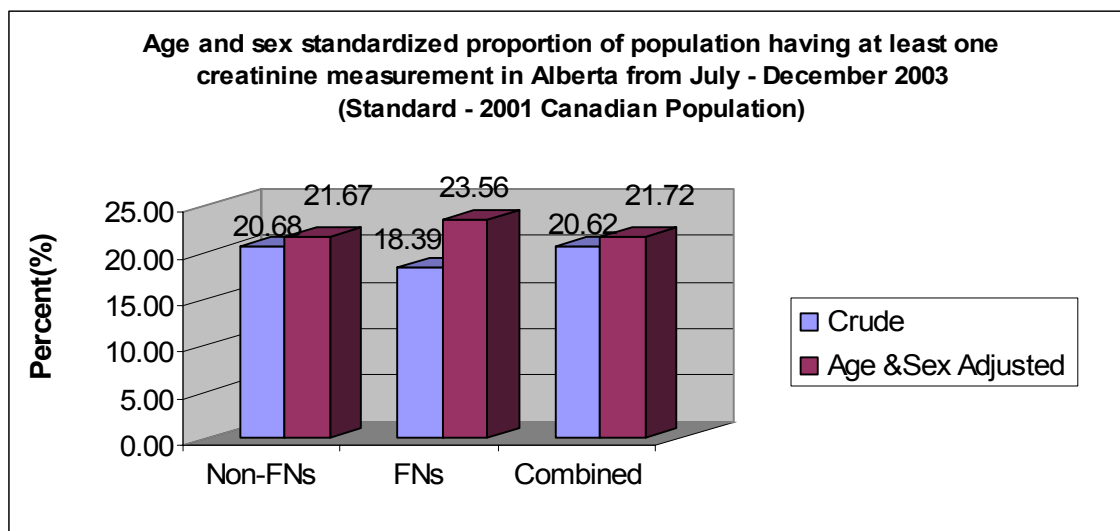


Figure 7. Age and Sex Standardized Prevalence of Measured CKD in Alberta July to December 2003, by First Nations Status

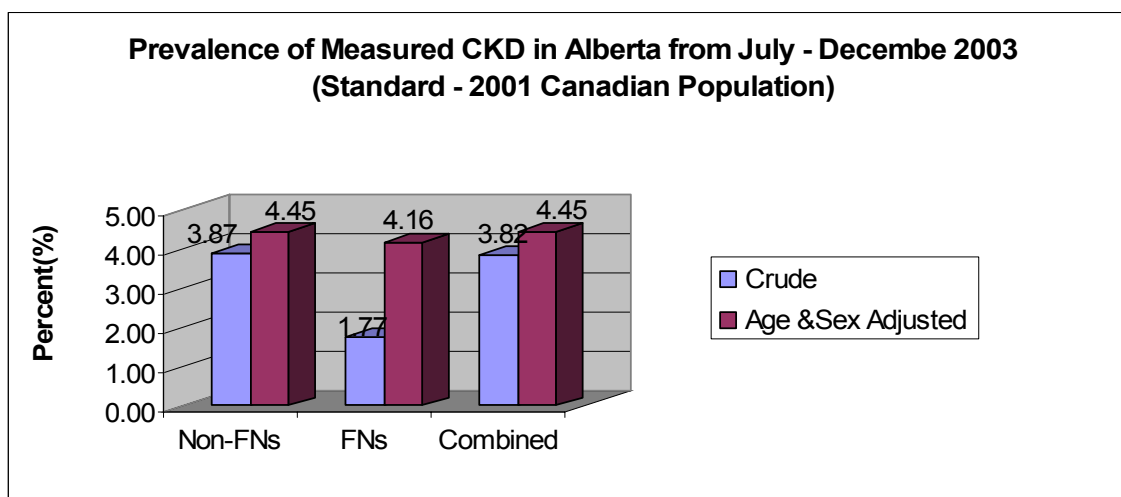


Figure 8. Age and Sex Stratified Prevalence of Measured CKD in Alberta, July to December 2003, by First Nations Status

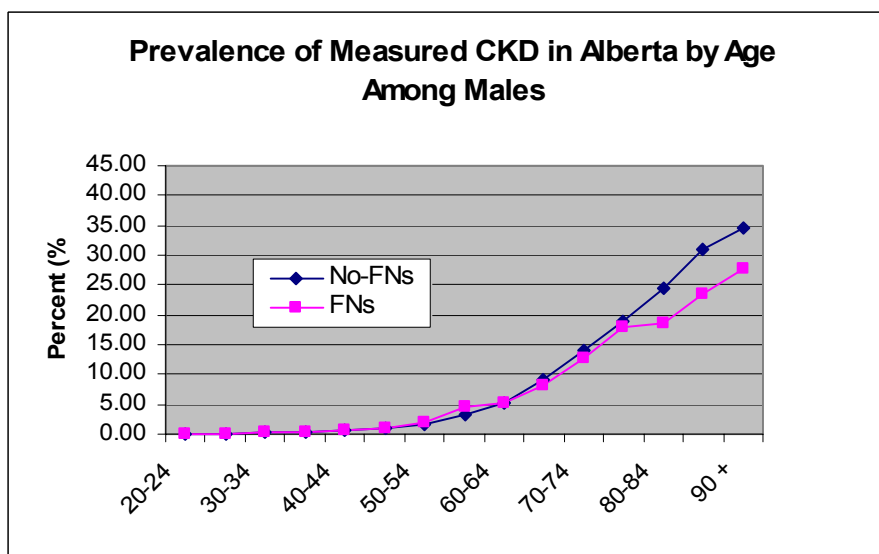
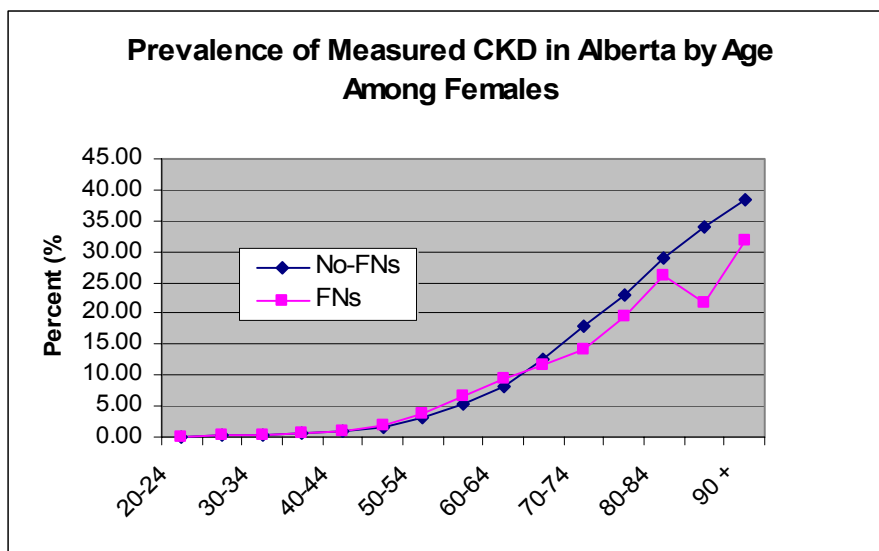
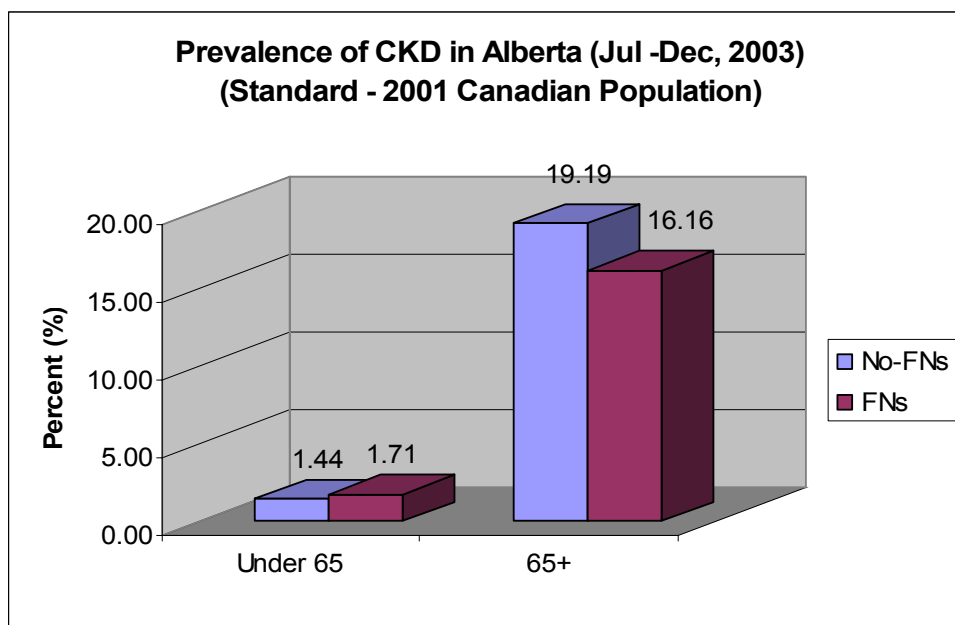


Figure 9. Age and Sex Standardized Prevalence of Measured CKD in Alberta, July to December 2003, by Age Group and First Nations Status



Appendix 1. Aboriginal Population, 2001 Counts, for Canada, Provinces and Territories

Name	Total Population	Aboriginal	First Nations	Métis	Inuit
Canada	29,639,030	976,305	608,850	292,305	45,070
Newfoundland and Labrador	508,080	18,775	7,040	5,480	4,560
Prince Edward Island	133,385	1,345	1,035	220	20
Nova Scotia	897,565	17,010	12,920	3,135	350
New Brunswick	719,710	16,990	11,495	4,290	155
Quebec	7,125,580	79,400	51,125	15,855	9,530
Ontario	11,285,545	188,315	131,560	48,340	1,375
Manitoba	1,103,700	150,045	90,340	56,800	340
Saskatchewan	963,155	130,185	83,745	43,695	235
Alberta	2,941,150	156,225	84,995	66,060	1,090
British Columbia	3,868,875	170,025	118,295	44,265	800
Yukon Territory	28,520	6,540	5,600	535	140
Northwest Territories	37,100	18,730	10,615	3,580	3,910
Nunavut	26,665	22,720	95	55	22,560

Data Source: Census Canada 2001 Cat. No. 97F0024XIE2001007

Appendix 2. Registered First Nations Population and Area of Residence in Alberta in 2001

Title	Registered First Nations
Total	80,775 *
Area of residence	
On reserve	36,360
Total off reserve	44,410
Rural non-reserve	9,900
Total urban	34,515 *
Urban non-census metropolitan area	12,605
Urban census metropolitan area	21,905

Data Source: Statistics Canada - Cat. No. 97F0011XCB2001005

* Numbers don't sum up to total because of rounding

Appendix 3. Definitions of Chronic Diseases Used in the Study

Chronic Diseases	ICD-9 Category
Renal Related	
Disorders of fluid, electrolyte, and acid-base balance	276
Nephritis, nephrotic syndrome, and nephrosis	580 – 589
Pyelonephritis	590
Hydronephrosis	591
Calculus of kidney and ureter	592
Other disorders of kidney and ureter	593
Proteinuria	791
Diabetes Related	
Diabetes mellitus	250
Vascular Related	
Disorder of lipid metabolism	272.0 - 272.9
Hypertension	401 - 405
Myocardial infarction	410
Other ischemic heart diseases	411 - 414
Diseases of pulmonary circulation	415 - 417
Congestive heart disease	428
Other forms of heart disease	420 – 427, 429
Hemorrhagic stroke	430 - 432
Ischemic stroke	433 - 434
Transient ischemic attacks	435
Other forms of stroke	436 - 438
Atherosclerosis	440
Aortic aneurysm and dissection	441
Other aneurysm	442
Other peripheral vascular disease	443
Arterial embolism and thrombosis	444

Appendix 4. Copy of Ethical Approval

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OFFICE OF MEDICAL BIOETHICS

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FACULTY OF MEDICINE

Office of Medical Bioethics
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2003-10-02

Asst. Professor B. Hemmelgarn
Division of Nephrology
Foothills Medical Center
1403 29th Street NW
Calgary, AB T2N 2T9

Dear Asst. Professor Hemmelgarn:

RE: Chronic Kidney Disease Among Aboriginal People in Alberta; Prevalence, Progression and Access to Care

Grant-ID: 17305

The above-named research project has been granted ethical approval by the Conjoint Health Research Ethics Board of the Faculties of Medicine, Nursing and Kinesiology, University of Calgary, and the Affiliated Teaching Institutions. The Board conforms to the Tri-Council Guidelines, ICH Guidelines and amendments to regulations of the Food and Drug Act re clinical trials, including membership and requirements for a quorum.

The study meets the requirements of the Health Information Act.

You and your co-investigators are not members of the CHREB and did not participate in review or voting on this study.

Please note that this approval is subject to the following conditions:

- (1) you must obtain approval from your appropriate institution where the research project will be conducted (if applicable).
- (2) a copy of the informed consent form must have been given to each research subject, if required for this study.
- (3) a Progress Report must be submitted in one year, 2004-10-02, containing the following information:
 - (i) the number of subjects recruited;
 - (ii) a description of any protocol modification;
 - (iii) any unusual and/or severe complications, adverse events or unanticipated problems involving risks to subjects or others, withdrawal of subjects from the research, or complaints about the research;
 - (iv) a summary of any recent literature, finding, or other relevant information, especially information about risks associated with the research;
 - (v) a copy of the current informed consent form;
 - (vi) the expected date of termination of this project.
- (4) a Final Report must be submitted at the termination of the project.

Please accept the Board's best wishes for success in your research.

Yours sincerely,

Christopher J. Doig, MD, MSc, FRCPC
Chair, Conjoint Health Research Ethics Board

CJD/am

c.c. Child Health Research Committee
Dr. J. Conly (information)
Research Services

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