

 UNIVERSITY OF ALBERTA  
FACULTY OF MEDICINE & DENTISTRY

**Clinical Research Seminar Series**  
October 10, 2017

***Administrative Health Data***  
Drs. Aminu Bello & Padma Kaul

 UNIVERSITY OF ALBERTA  
FACULTY OF MEDICINE & DENTISTRY  NACTRC  
Northern Alberta Clinical  
Trials Research Centre

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 UNIVERSITY OF ALBERTA  
FACULTY OF MEDICINE & DENTISTRY

PART I

***Administrative Health Data***  
Dr. Padma Kaul

 UNIVERSITY OF ALBERTA  
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 Canadian **VIGOUR** Centre  
Bridging Hearts and Minds

**Administrative Health Data**  
An Application to Research in Alberta  
October 10, 2017

Padma Kaul, PhD  
Professor, Division of Cardiology  
Department of Medicine

NACTRAC Clinical Research Seminar Series

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## Developmental Origins of Health and Disease

**TIME**

How the first nine months shape the rest of your life

The new science of fetal origins

Endowment Special: The occasion—why 20% of our planet is in danger. The Facebook Meets: The secret history of social networking.




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## Population Health Data, Alberta, Canada (pop 4.1 million)

INPATIENT	OUTPATIENT	DRUG CLAIMS	PHYSICIAN CLAIMS	LABS	BIRTH REGISTRY	VITAL STATUS
Dx, Procs, co-morbid conditions, LOS, costs	ED use; specialty clinics	Medication use	Follow-up care; provider factors	Bio-markers	Birth details	Mortality
Unique patient identifier						




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## Alberta Pregnancy-Birth Cohort

Current data: 321,080 women  
Median length of follow-up: 8 – 9 years

Cohort start 01/04/2005    Lab and drugs available 01/04/08    Follow-up data available 01/04/15

Current data: 496,158 babies  
Median length of follow-up: 5 years

Cohort start 01/04/05    Lab and drugs available 01/04/08    Follow-up data available 01/04/15




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### Realm of "big data"

Description	N
# Infants	496,158
# Mothers	321,080
# Hospitalizations (Mothers)	1,126,706
# Hospitalizations (Infants)	621,016
# Outpatient (NACRS) visits (Mothers)	11,313,060
# Outpatient (NACRS) visits (Infants)	4,933,699
# Physician claims (Mothers)	69,611,314
# Physician claims (Infants)	16,659,359
# Pharmaceutical claims (Mothers)	18,633,440
# Pharmaceutical claims (Infants)	4,061,724
# Laboratory tests (Mothers and Infants)	68,743,113




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### Gestational Diabetes Mellitus (GDM)

- Greatest rise in diabetes in young women aged 20 - 49 years
- GDM is glucose intolerance first recognized during pregnancy
  - typically after 20 weeks gestation
  - generally temporary, resolves post partum
  - established risk factor for T2DM
- Increasing maternal age and obesity major factors contributing to GDM rates




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### Characteristics of women giving birth in Alberta

- Mean age 29±6 years
- Proportion ≥ 35 years –16%
- 43% giving birth for the first time
- 83% live in urban areas
- 20% smoked during pregnancy
- Pre-existing risk factors (10%)




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**ADSS** Alberta Diabetes Surveillance System

## Alberta Diabetes Surveillance System

**ADSS** **CHAPTER 12** Alberta Diabetes Surveillance System

### GESTATIONAL DIABETES IN ALBERTA

**KEY MESSAGES**

- Rates of gestational diabetes mellitus have increased by 50% in the past decade.
- Rates of GDM are substantially higher in women over the age of 35 years.
- Aboriginal women have greater rates of GDM compared to the general population.

Kaul, et al Alberta Diabetes Atlas 2011

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**ADSS** Alberta Diabetes Surveillance System

## Alberta Diabetes Surveillance System

**Figure 12.1 Gestational Diabetes Cases, 1998-2009**

Year	Number of Cases (Age 15-54)
1998	710
1999	750
2000	766
2001	872
2002	899
2003	817
2004	921
2005	981
2006	1,273
2007	1,300
2008	1,293
2009	1,430

Kaul, et al Alberta Diabetes Atlas 2011

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## Validity of administrative data?

DIABETIC.Medicine  
DOI: 10.1111/dme.13030

**Short Report: Epidemiology**  
**Validation of administrative data case definitions for gestational diabetes mellitus**

S. L. Bowker<sup>1</sup>, A. Savu<sup>2</sup>, N. K. Lam<sup>3</sup>, J. A. Johnson<sup>1</sup> and P. Kaul<sup>2,3</sup>

<sup>1</sup>School of Public Health, <sup>2</sup>Canadian VIGOUR Centre and <sup>3</sup>Faculty of Medicine and Dentistry, University of Alberta, Edmonton, Alberta

Accepted 4 November 2015

**Abstract**

**Aim** To examine, using administrative data, the validity of two algorithms for identifying gestational diabetes mellitus: 1) the current National Diabetes Surveillance System algorithm for excluding gestational diabetes cases and 2) gestational diabetes-specific ICD codes in the delivery-related hospitalization.

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## Variability in GDM rates across provinces

TABLE 2: Rates of GDM, by province and territory, Canada, 2004/05–2010/11

PROVINCE/TERRITORY	RATE PER 1,000 DELIVERIES	95% CI
Newfoundland and Labrador	36.0	33.9–38.1
Prince Edward Island	20.6	17.9–23.7
Nova Scotia	36.6	35.0–38.1
New Brunswick	33.3	31.8–35.0
Ontario	44.0	43.6–44.4
Manitoba	40.9	39.7–42.1
Saskatchewan	37.7	36.5–39.0
Alberta	44.3	43.6–45.1
British Columbia	73.7	72.7–74.7
Yukon	44.5	36.5–53.7
Northwest Territories	21.5	17.8–25.7
Nunavut	11.7	8.0–16.7
Canada	47.1	46.8–47.5

SOURCE: Canadian Institute for Health Information, Discharge Abstract Database (DAD). Quebec data was not included because it does not contribute to DAD



Source: PHAC Report Maternal Diabetes in Canada

## Ethnicity of women giving birth in Alberta

Algorithms based on patient surname

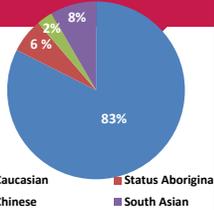


image credit: HSCF

## Role of ethnicity in GDM

Journal of Diabetes and Its Complications 31 (2017) 528–536

Contents lists available at ScienceDirect

Journal of Diabetes and Its Complications

Journal homepage: [WWW.JDCJOURNAL.COM](http://WWW.JDCJOURNAL.COM)



### Prevalence of gestational diabetes among Chinese and South Asians: A Canadian population-based analysis

Roseanne O. Yeung <sup>a,\*</sup>, Anamarie Savu <sup>b</sup>, Brooke Kinniburgh <sup>c</sup>, Lily Lee <sup>d</sup>, Susie Dzakpasu <sup>e</sup>, Chantal Neblon <sup>f</sup>, Jeffrey A. Johnson <sup>g</sup>, Lois E. Donovan <sup>h</sup>, Edmond A. Ryan <sup>i</sup>, Padma Kaul <sup>h,\*</sup>

<sup>a</sup> Division of Endocrinology and Metabolism, 9114 - Clinical Sciences Building, University of Alberta, 1120J - 83 Avenue, Edmonton, Alberta, T6G 2G3, Canada  
<sup>b</sup> Division of Cardiology, Canadian Vignar Centre, 2-132 JJ KA Oling Centre for Health Research Innovation, University of Alberta, Edmonton, AB T6G 2E1, Canada  
<sup>c</sup> Perinatal Services BC, West Fraser, Suite 200, 935 W. 5th Avenue, Vancouver, BC, V5Z 3G7, Canada  
<sup>d</sup> Public Health Agency of Canada, 295 Carling Avenue, Ottawa, Ontario, K1A 0K9, Canada  
<sup>e</sup> School of Public Health, University of Alberta, 2-840114 KA Oling Centre for Health Research Innovation, Edmonton, AB, T6G 2E1, Canada  
<sup>f</sup> Division of Endocrinology, University of Calgary, Richmond Rd Diagnostic and Treatment Centre, 1420 Richmond Rd, SW, Calgary, AB, T2P 3C7, Canada

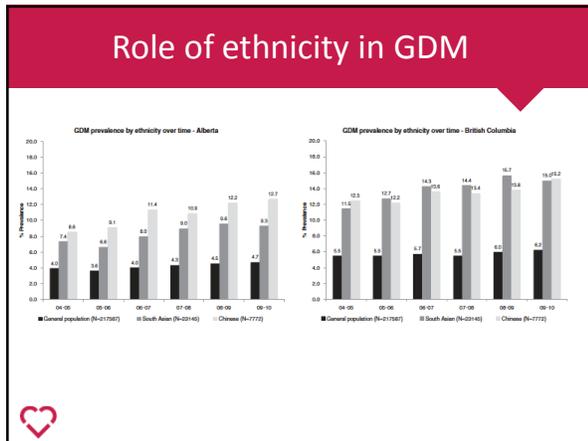
#### ARTICLE INFO

Article history:  
 Received 10 June 2016  
 Received in revised form 11 October 2016

#### ABSTRACT

**Background:** There is considerable geographic variation in gestational diabetes mellitus (GDM) rates. We used data from two Canadian provinces, British Columbia (BC), and Alberta (AB), to determine the impact of ethnicity on GDM prevalence and neonatal outcomes.






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### Intersection between GDM and other conditions during pregnancy

**Clinical Research**  
**Association Between Diabetes During Pregnancy and Peripartum Cardiomyopathy: A Population-Level Analysis of 309,825 Women**

Sumandeep Dhesi, MD,<sup>a</sup> Anamaria Savu, PhD,<sup>b</sup> Justin A. Ezekowitz, MBBCh, MSc,<sup>c</sup> and Padma Kaul, PhD<sup>d</sup>

<sup>a</sup>Division of Cardiology, University of Alberta, Mazankowski Alberta Heart Institute, Alberta, Canada  
<sup>b</sup>Canadian VIGOUR Centre, University of Alberta, Alberta, Canada  
<sup>c</sup>Division of Cardiology, University of Alberta, Mazankowski Alberta Heart Institute, Canadian VIGOUR Centre, Edmonton, Alberta, Canada  
<sup>d</sup>Division of Cardiology, University of Alberta, Mazankowski Alberta Heart Institute, Canadian VIGOUR Centre, Alberta, Canada

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### Intersection between GDM and other conditions during pregnancy

Can J Diabetes xxx (2017) 1–7

Contents lists available at ScienceDirect

Canadian Journal of Diabetes

Journal homepage: [www.canadianjournalofdiabetes.com](http://www.canadianjournalofdiabetes.com)

**Original Research**  
**Development of Perinatal Mental Illness in Women With Gestational Diabetes Mellitus: A Population-Based Cohort Study**

Qendresa Beka MSc<sup>a,\*</sup>, Samantha Bowker PhD<sup>a</sup>, Anamaria Savu PhD<sup>a</sup>, Dawn Kingston PhD<sup>b</sup>, Jeffrey A. Johnson PhD<sup>a</sup>, Padma Kaul PhD<sup>a</sup>

<sup>a</sup> University of Alberta, Edmonton, Alberta, Canada  
<sup>b</sup> University of Calgary, Edmonton, Alberta, Canada

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## Long-term outcomes associated with GDM

DIABETICMedicine  
DOI: 10.1111/dme.12635

### Research: Pregnancy

### Impact of gestational diabetes mellitus and high maternal weight on the development of diabetes, hypertension and cardiovascular disease: a population-level analysis

P. Kaul<sup>1</sup>, A. Savu<sup>1</sup>, K. A. Nerenberg<sup>2</sup>, L. E. Donovan<sup>3</sup>, C. L. Chik<sup>1</sup>, E. A. Ryan<sup>1</sup> and J. A. Johnson<sup>1</sup>

<sup>1</sup>University of Alberta, Edmonton, Alberta, <sup>2</sup>University of Ottawa, Ottawa, Ontario and <sup>3</sup>University of Calgary, Calgary, Alberta, Canada  
Accepted 14 November 2014




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## Long-term outcomes associated with GDM

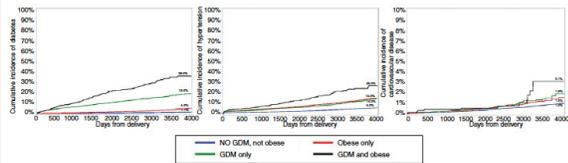


FIGURE 2 Cumulative incidence of diabetes (panel 1), hypertension (panel 2) and cardiovascular disease (panel 3) by maternal gestational diabetes mellitus and weight status.




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## Population Health Data, Alberta, Canada (pop 4.1 million)

INPATIENT	OUTPATIENT	DRUG CLAIMS	PHYSICIAN CLAIMS	LABS	BIRTH REGISTRY	VITAL STATUS
Dx, Procs, co-morbid conditions, LOS, costs	ED use; specialty clinics	Medication use	Follow-up care; provider factors	Bio-markers	Birth details	Mortality

Unique patient identifier




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**Canadian Mother-Child Cohort: Canadian Multi-Province Cohorts of Pregnant Women and Children**



- The national cohort will align pregnancy and birth cohort data from **six provinces** (British Columbia (BC), Manitoba (MB), Saskatchewan (SK), Ontario (ON), Quebec (QC), and Alberta (AB)).
- Expected number of deliveries: 8 M



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**Collaborators**

- University of Alberta
  - Dr. Anamaria Savu
  - Dr. Sam Bowker
  - Dr. Eddie Ryan
  - Dr. Rose Yeung
- University of Calgary
  - Dr. Lois Donovan
  - Dr. Sonia Butalia
  - Dr. Alun Edwards



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PART II  
**Administrative Health Data**  
Dr. Aminu Bello



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## Administrative Health Data An Application to Research in Alberta

**Aminu Bello, MD, PhD, FRCP, FACP**  
Assistant Professor/Nephrologist  
Alberta Kidney Disease Network  
University of Alberta

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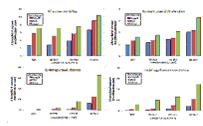
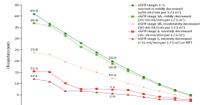
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### Kidney disease is common, and a significant public health problem



- ~1 in 10 adults in Canada have CKD
- ~40,000 on RRT in Canada consuming ~2% of total healthcare budget
- CKD is associated with a high risk of adverse CV outcomes
- CKD is associated with significant mortality and loss of QoL
- The average life expectancy of a patient on dialysis is 5 years (2 years if >75 yrs old)
- The average life expectancy of a patient who starts dialysis in their late 20's is about 20 years

Hemmelgarn et al, 2011; Gansevoort et al, 2012

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### My objectives in this presentation

- An overview of AKDN administrative database
- Discuss the applications of admin database to kidney research
- Outline a specific example in Alberta on geography and kidney health, and the relevant clinical and policy impact
- Discuss of some pitfalls and limitations of admin databases for clinical research

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### Background

- The Alberta Kidney Disease Network (AKDN) is a collaborative group of researchers
- A unique data collection initiative of routine laboratory tests on all individuals in the province
- Individuals identified from lab data are linked to administrative and other computerized sources

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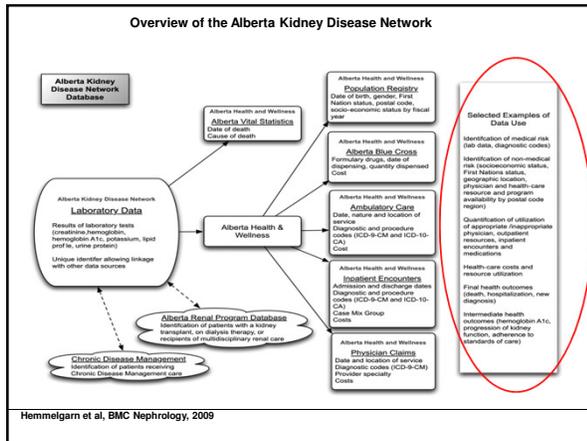
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### Some of the objectives of the AKDN

- To determine:
  - the prevalence and identify those at high risk for CKD in Alberta
  - rates of progression to kidney failure in patients with CKD
  - If access to and quality of CKD care differs by socio-demographics, location of residence or ethnic background
  - the health care costs of caring for patients with CKD
  - determine optimal treatments for patients with CKD

Hemmelgarn et al, BMC Nephrology, 2009

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**Impact of residence location on quality of care and health outcomes**

- Initial emphasis on renal replacement therapy (dialysis and transplantation)
- Renewed emphasis on CKD as a public health issue
- Various CKD subgroups
  - All
  - Targeted: DM, Proteinuric

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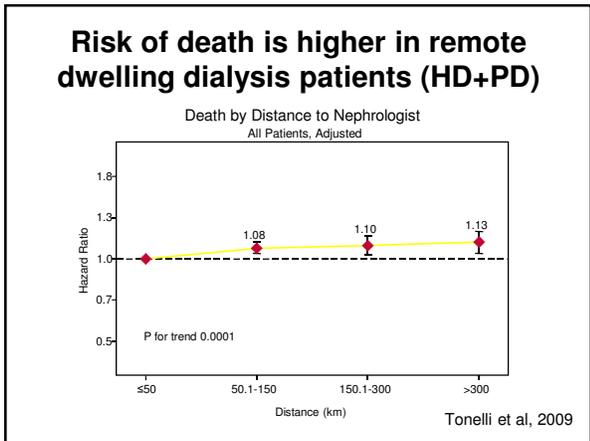
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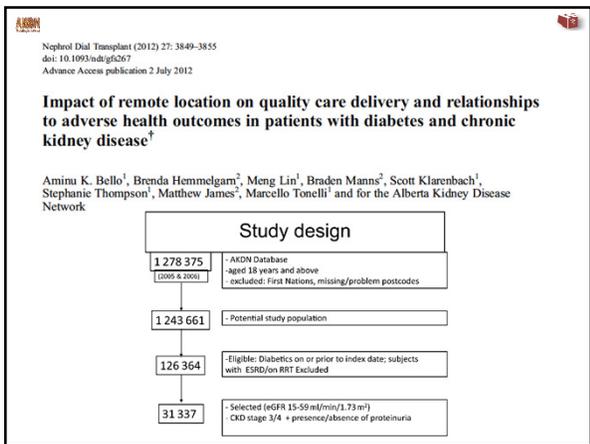
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### Objectives of the study

Using a large community-based cohort to investigate:

1. The prevalence of CKD among rural/remote dwellers of Alberta
2. Quality of care received compared to the Urban dwellers
3. Relationships of quality of care and clinical outcomes

Bello et al, 2012

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### Study outcomes

1. **Prevalence of CKD** among rural/remote dwellers of Alberta
2. **Process-based care**
  - Access to specialist kidney care
  - Use of recommended medications - prescription for an ACEi/ARB and/or statins
3. **Clinical events**
  - All-cause mortality and all-cause hospitalizations
  - Cardiovascular (CHF, MI, Stroke)
  - Kidney (ESRD, progression of CKD)

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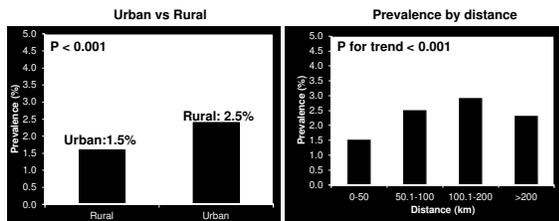
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### There was a high burden of CKD in remote/rural dwellers compared to those living in the urban settings

Prevalence of CKD 40% higher in Rural Dwellers

CKD more common in Remote Dwellers




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## Summary

- Even in a universal healthcare system, rural/remote dwellers with CKD (compared to urban-dwellers):
  - Have a higher burden of the disease
  - less likely to receive specialist care
  - less likely to be prescribed recommended medications
  - more likely to have an adverse clinical event (eg stroke) or be hospitalized

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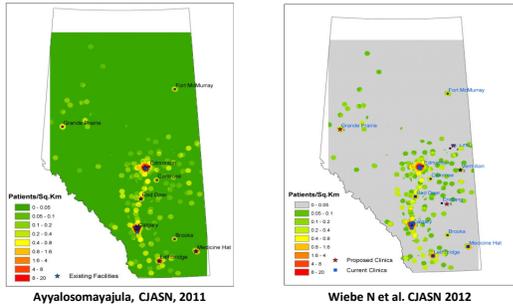
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## What can be done to close the gaps in care: potential solutions

new care facilities/clinics




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## Leveraging information technology to deliver care through e-Consult

- The existing CKD clinical pathway will alert the PCPs to high risk CKD patients and direct them to the e-referral/consultation system in Netcare or the PCP will initiate referral when deemed necessary with questions
- Specialist reply within a week or less - options:
  - Specific reply to question
  - Request more information
  - Recommend a referral (along with any actions/tests to be completed beforehand)
- PCP can follow up with additional information, clarification, and/or question if necessary
- PCP will ultimately close the case

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### Strengths of admin data in clinical research

Administrative databases have some advantages over data obtained from primary surveys or studies

- **Real-world health data**
- **A wider population coverage with longer follow-up periods than what is possible in primary studies**
- Medicare provides data on over 96% of the elderly and all patients on RRT in the US
- AKDN contains data on over 3 million Albertans with nearly 15 years of follow-up data on measurements and outcomes
- **Comprehensiveness (socio-demographics, healthcare utilization, outcomes data on events and costs) and potential linkages with other sources**
- **More cost effective to obtain than the primarily studies or surveys**

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### Some limitations worthy of mention

- Usually not obtained primarily for research purposes
- Limited to records obtained for the purpose of reimbursement (i.e. physician claims and drug benefits), or tracking healthcare service delivery (i.e. hospitalizations or ER use)
- Important clinical data such as BP and lifestyle variables (smoking, exercise and diet) and other important information like patient satisfaction and psychological impact of care may be missing
- Knowledge gaps associated with these inherent limitations could be addressed using targeted primary surveys or studies

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### Conclusions

- Administrative databases provide opportunities for defining disease epidemiology, quality of care and related outcomes
- Good source for defining **gaps in care** to develop strategies aimed at ensuring equity
- Used to capture the impact of applied interventions **to close any identified gaps in care**
- Useful for setting policy goals targeted to improving quality of care in any disease domain
- Huge opportunities in Alberta with admin data access through the **SPOR data platform and other related initiatives**

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