Clinical Research Seminar Series
October 10, 2017

Administrative Health Data
Drs. Aminu Bello & Padma Kaul

PART I

Administrative Health Data
Dr. Padma Kaul

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
Developmental Origins of Health and Disease

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

Alberta Pregnancy-Birth Cohort

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

Current data: 496,158 babies
Median length of follow-up: 5 years
### Realm of “big data”

<table>
<thead>
<tr>
<th>Description</th>
<th>N</th>
</tr>
</thead>
<tbody>
<tr>
<td># Infants</td>
<td>496,158</td>
</tr>
<tr>
<td># Mothers</td>
<td>121,080</td>
</tr>
<tr>
<td># Hospitalizations (Mothers)</td>
<td>1,226,706</td>
</tr>
<tr>
<td># Hospitalizations (Infants)</td>
<td>621,016</td>
</tr>
<tr>
<td># Outpatient (NACRS) visits (Mothers)</td>
<td>11,333,060</td>
</tr>
<tr>
<td># Outpatient (NACRS) visits (Infants)</td>
<td>4,133,689</td>
</tr>
<tr>
<td># Physician claims (Mothers)</td>
<td>69,611,345</td>
</tr>
<tr>
<td># Physician claims (Infants)</td>
<td>16,609,359</td>
</tr>
<tr>
<td># Pharmaceutical claims (Mothers)</td>
<td>18,633,440</td>
</tr>
<tr>
<td># Pharmaceutical claims (Infants)</td>
<td>4,061,724</td>
</tr>
<tr>
<td># Laboratory tests (Mothers and Infants)</td>
<td>68,743,113</td>
</tr>
</tbody>
</table>

### 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

### 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%)
VALIDITY OF ADMINISTRATIVE DATA?

Short Report: Epidemiology
Validation of administrative data case definitions for gestational diabetes mellitus
S. L. Boukhan, A. Savu, N. K. Lai, J. A. Johnson and P. Kaul

Abstract

To compare, 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 code in the delivery-related hospitalization.
Pre-pregnancy
Age, weight, diabetes, hypertension, heart disease
Past Obstetrical history
Neonatal deaths, c-sections
Problems w/ Current pregnancy
GDM, anemia, bleeding,
Other risk factors
Smoking, Drug use, alcohol use
Pregnancy details
Gestational age, Induction, C-section
Neonatal outcomes
Still birth, neonatal death

Validity of different algorithms to identify GDM cases

Validation using lab data as gold standard

Short Report: Epidemiology
Validation of administrative and clinical case definitions for gestational diabetes mellitus against laboratory results
S. L. Baseler, A. Saw, J. E. Donovan, J. A. Johnson and P. Kaufman
1School of Public Health, University of Alberta, Edmonton; 2University of Calgary, University of Alberta, Edmonton, Department of Medicine, University of

5
Who is screened for GDM?

Prevalence and Timing of Screening and Diagnostic Testing for Gestational Diabetes Mellitus: A Population-Based Study in Alberta, Canada

Impact of different diagnostic definitions for GDM

Original article
Population-Level Outcomes with a 2-Step Approach for Gestational Diabetes Screening and Diagnosis

Impact of different diagnostic definitions for GDM

<table>
<thead>
<tr>
<th>Year</th>
<th>Number of Pregnancies</th>
<th>New Diagnoses</th>
<th>Gestational Diabetes Mellitus (GDM)</th>
</tr>
</thead>
<tbody>
<tr>
<td>2015</td>
<td>10,000</td>
<td>500</td>
<td>10%</td>
</tr>
<tr>
<td>2016</td>
<td>12,000</td>
<td>600</td>
<td>15%</td>
</tr>
<tr>
<td>2017</td>
<td>15,000</td>
<td>750</td>
<td>25%</td>
</tr>
</tbody>
</table>

*Note: The data is based on a population-based study conducted in Alberta, Canada.*
Variability in GDM rates across provinces

<table>
<thead>
<tr>
<th>PROVINCE/TERREITORY</th>
<th>RATE PER 1,000 DELIVERIES</th>
<th>95% CI</th>
</tr>
</thead>
<tbody>
<tr>
<td>Newfoundland and Labrador</td>
<td>34.0</td>
<td>15.3–54.3</td>
</tr>
<tr>
<td>Prince Edward Island</td>
<td>20.6</td>
<td>11.9–29.7</td>
</tr>
<tr>
<td>Nova Scotia</td>
<td>28.6</td>
<td>20.5–39.1</td>
</tr>
<tr>
<td>New Brunswick</td>
<td>33.3</td>
<td>11.8–55.0</td>
</tr>
<tr>
<td>Ontario</td>
<td>44.0</td>
<td>43.6–44.4</td>
</tr>
<tr>
<td>Maryland</td>
<td>49.9</td>
<td>39.7–62.1</td>
</tr>
<tr>
<td>Saskatchewan</td>
<td>32.3</td>
<td>26.5–39.0</td>
</tr>
<tr>
<td>Alberta</td>
<td>44.5</td>
<td>42.6–46.1</td>
</tr>
<tr>
<td>British Columbia</td>
<td>79.3</td>
<td>72.7–87.7</td>
</tr>
<tr>
<td>Yukon</td>
<td>44.5</td>
<td>36.5–53.7</td>
</tr>
<tr>
<td>Northwest Territories</td>
<td>27.3</td>
<td>17.8–37.7</td>
</tr>
<tr>
<td>Nunavut</td>
<td>11.7</td>
<td>8.0–16.1</td>
</tr>
<tr>
<td>Canada</td>
<td>47.1</td>
<td>46.8–47.3</td>
</tr>
</tbody>
</table>

Source: PHAC Report Maternal Diabetes in Canada

Ethnicity of women giving birth in Alberta

Algorithms based on patient surname

Role of ethnicity in GDM

Journal of Diabetes and Its Complications

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

ARTICLE INFO

Article history and availability on 2017.04.04

Abstract

Examines the prevalence of gestational diabetes mellitus (GDM) among Chinese and South Asian women in Canada. The study uses population-based data from the Canadian Diabetes Registry to analyze the risk factors associated with GDM among women of Chinese and South Asian descent. Findings indicate a higher prevalence of GDM among women with Chinese and South Asian ethnicity compared to Caucasian women. The study highlights the importance of cultural and ethnic considerations in the prevention and management of gestational diabetes.
Role of ethnicity in GDM

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
Sanneh Dukasi, MD, Ana Maria Savu, PhD, Justin A. Enderwit, MBCH, MSc, and Padma Kaul, PhD

Intersection between GDM and other conditions during pregnancy

Original Research
Development of Perinatal Mental Illness in Women With Gestational Diabetes Mellitus: A Population-Based Cohort Study
Qendra Beka MSc, Sambha Bowler PhD, Ana Maria Savu PhD, Dawn Kingston PhD, Jeffrey A. Johnson PhD, Padma Kaul PhD
Long-term outcomes associated with GDM

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. Kaul1, A. Saru1, K. A. Nerenberg2, L. E. Donovan3, C. L. Chik1, E. A. Ryan3 and J. A. Johnson1

1University of Alberta, Edmonton, Alberta, University of Ottawa, Ottawa, Ontario and 2University of Calgary, Calgary, Alberta, Canada

Accepted: 16 November 2016

Population Health Data, Alberta, Canada (pop 4.1 million)
## Low birth weight in Alberta

<table>
<thead>
<tr>
<th>Province/Territory</th>
<th>Low Birth Weight Rate (95% CI)</th>
<th>Preterm Birth Rate (95% CI)</th>
<th>Small-For-Gestational-Age Rate (95% CI)</th>
</tr>
</thead>
<tbody>
<tr>
<td>Alberta</td>
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<tr>
<td>British Columbia</td>
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<td>Manitoba</td>
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<td>New Brunswick</td>
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<td>Newfoundland and Labrador</td>
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<td>Prince Edward Island</td>
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<td>Quebec</td>
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<td>Saskatchewan</td>
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<td>Yukon</td>
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</table>

From: Highlights of 2010-2011 Selected Indicators Describing the Birthing Process in Canada
Source: Canadian Institutes of Health Information

## Low birth weight in Alberta

The Journal of Pediatrics • www.jpeds.com

Health Service Use and Costs Associated with Low Birth Weight—A Population Level Analysis

Nguyen Huu Thanh, MD, MPH, PhD; Jennifer Tse, MD, FRCP, BC, MPH; Aernas Dao, PhD; Monj Kumar, MD; and Padma Kaul, PhD.

Objectives: To examine differences in health services utilization (HUSU) and the first year of life between low birth weight (LBW) and normal birth weight (NBW) infants, identify maternal- and child-characteristics associated with HUSU costs, and estimate annual HUSU cost of LBW infants for the province of Alberta, Canada.

## Prescription drug use during pregnancy and long-term health outcomes in the mother and child

Padma Kaul, PhD
Professor, Department of Medicine
University of Alberta

R Greiner; A Metcalfe; T Oberlander; B Carleton; B Winquist; A Berard
Canadian Mother-Child Cohort: Canadian Multi-Provinc e 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

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

PART II
Administrative Health Data
Dr. Aminu Bello
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

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 20s is about 20 years

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
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

Overview of the Alberta Kidney Disease Network

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
Real life application of data to enhance optimal care and contribute to policy formulation

NDT

Use of administrative databases for health-care planning in CKD

Antoon Belch, Brenda Hemminger, Brenda Mann, Marcello Tonelli and for Alberta Kidney Disease Network.

1Departments of Medicine and Public Health Sciences, University of Alberta, Edmonton, AB, Canada and 2Departments of Medicine and Community Health Sciences, University of Calgary, Calgary, AB, Canada

CHALLENGE

Vast geography, travel distance & sparsely distributed health centers

- Large catchment area plus responsibility for NWT, and adjoining communities of BC and Saskatchewan
- Low population densities in remote areas, and nephrologists mainly located in Edmonton and Calgary
- Health centers located far in-between, and patients have to travel long distances to access specialist kidney care (in some places >1000 km!)

<table>
<thead>
<tr>
<th>Land area (km²)</th>
<th>% of national land area</th>
<th>Population size</th>
</tr>
</thead>
<tbody>
<tr>
<td>Alberta</td>
<td>642,317</td>
<td>7.1%</td>
</tr>
<tr>
<td>NWT</td>
<td>1,183,085</td>
<td>13.0%</td>
</tr>
<tr>
<td>Ontario</td>
<td>917,741</td>
<td>10.1%</td>
</tr>
</tbody>
</table>

A research to guide policy and action
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

Risk of death is higher in remote dwelling dialysis patients (HD+PD)

Death by Distance to Nephrologist

All Patients, Adjusted

Tonelli et al, 2009
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

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)

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

Prevalence by distance
>80% of patients with proteinuric CKD have not seen a kidney specialist

Use of recommended medications (ACEI/ARB) is lower than optimal among the remote/rural dwellers

All-cause hospitalization more likely during follow-up in rural/remote dwellers

Risk of stroke is higher in remote dwellers
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 (e.g., stroke) or be hospitalized

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

- New care facilities/clinics
  - Ayyalosomayajula, CJASN, 2011
  - Wiebe N et al. CJASN 2012

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
CKD Clinical Pathway

Initiation of referral
Demographics & clinical information ( creatinine, proteinuria, BP, CV risk etc.)

Nephrologist-on-call
Decision steps:
1. etiology of the CKD
2. renal risk assessment
3. CV risk evaluation

Patient needs to be seen:
- additional required investigations
- appointment
- initial steps (urgent start of evaluation)
- summary for patient:
  - self management

Patient needs not to be seen:
- summary for PCP
- follow up details for PCP
- thresholds for re-referral
- summary for patient
- educational material for patient:
  - self management
  - BP, lifestyle

Branko Braam, 2014

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
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

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

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