Using Health Administrative Data for Primary Care Research

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Research Knowledge and Skills Builder
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Learning Objectives

Attendees will develop an understanding of:

1. Health administrative data
   1. The strengths and limitations of working with health administrative data.

2. ICES (formerly the Institute for Clinical Evaluative Sciences)

3. ICES health administrative data holdings in Ontario, Canada.

4. How researchers can work with ICES.

5. The types of primary care research that can be addressed using health administrative data.
What is health administrative data?

- Administrative data documents the provision of health services (i.e., OHIP, Medicare, etc.)
  - Data holdings were not initially developed for research purposes, compared to research surveys and databases.
- “Big Data” approach for healthcare research
Working with Health Administrative Data

**Strengths**

- Often include many years of data, allowing us to look at trends and patterns over time.
- Represent most people in the population (i.e., population-based), allowing us to look at differences among specific cohorts (i.e., demographic, health status, etc.).
- Access to detailed health data, allowing researchers to study health outcomes and health care utilization.
- Cost-effective for large sample size research as data is already collected.
- Limits information biases such as recall bias, observation bias, and reporting bias.
- Ability to link different administrative datasets together through ICES.

**Limitations**

- While prominent demographic information may be available (i.e., age, sex, socio-economic status), health admin data does not typically provide data on health behaviours.
- Can study association but not causation.
- Strictly quantitative which limits the scope of research questions/objectives.
What is ICES?

Formerly- Institute for Clinical Evaluative Sciences

• Not-for-profit research institute with access to Ontario’s health administrative data.
• Work with researchers to evaluate health care delivery and population outcomes.
• Access to health data for approximately 13 million people.
Where is ICES located?
# Types of ICES Data Available

<table>
<thead>
<tr>
<th>Health Services Administrative Data</th>
<th>People and Geography</th>
<th>Special Collections</th>
<th>Derived Conditions</th>
<th>Survey Data, Clinical Data, Chart Abstraction Data</th>
</tr>
</thead>
<tbody>
<tr>
<td>• Physician Billings</td>
<td>• Population estimates</td>
<td>• Registries (cancer, stroke, cardiac care)</td>
<td>• Diabetes</td>
<td>• Health surveys</td>
</tr>
<tr>
<td>• Prescription drug claims for those 65 and older</td>
<td>• Canada census profiles</td>
<td>• First Nations and Metis</td>
<td>• Hypertension</td>
<td>• Patient information collected with consent in primary clinical studies</td>
</tr>
<tr>
<td>• Inpatient hospital discharges</td>
<td>• Death records</td>
<td>• Developmental disabilities</td>
<td>• COPD</td>
<td>• Supplementary clinical data from individual hospitals and other institutions</td>
</tr>
<tr>
<td>• Emergency and ambulatory care visits</td>
<td>• All Ontarians eligible for health care benefits</td>
<td>• Federal immigration information</td>
<td>• Asthma</td>
<td>• Information on processes and quality of care collected directly from patients’ charts</td>
</tr>
<tr>
<td>• Homecare and rehabilitation claims</td>
<td></td>
<td></td>
<td>• Acute myocardial infarction</td>
<td></td>
</tr>
<tr>
<td>• Long-term care visits</td>
<td></td>
<td></td>
<td>• Congestive heart failure</td>
<td></td>
</tr>
</tbody>
</table>

For more information about data holdings available at ICES, please refer to the [ICES Data Dictionary](https://www.ices.on.ca/).
1. Identifying an ICES Scientist
2. Research Ethics Approval
3. Project Activation
4. Data Creation Plan
5. Project Kickoff & Data Analysis
6. Publication

ICES Project Cycle
1. Identifying an ICES Scientist

- Every ICES project must involve a full ICES Scientist.
  - Scientists have completed a 3-year probationary period
  - Able to support ICES projects

- ICES McMaster Scientists:
  - Michelle Howard, Hsien Seow (ICES Director), Jim Dunn, Andrew Costa

- A full list of scientists can be found [here](#).

ICES Project Cycle:

1. Identifying an ICES Scientist
2. Research Ethics Approval
3. Project Activation
4. Data Creation Plan
5. Project Kickoff & Data Analysis
6. Publication
Q&A Break
2. Research Ethics Board Approval

• The use of ICES data is authorized under section 45 of Ontario’s Personal Health Information Protection Act, which does not require a review by a Research Ethics Board.

• You will need REB approval if you plan to link ICES datasets with external datasets.
3. Project Activation

- All applicants must complete the following to activate a project:
  - Project Activation Worksheet (PAW)
  - Privacy Impact Assessments (PIA)
  - Non-Disclosure Agreements (NDA)
- PAWs describe study objectives, budget and billing information, and is used to assign a project (TRIM) number to the application.
- PIAs describe the research questions, access to required data holdings, project-specific data linkages (if applicable), and all project team members.
- Project team members must submit signed NDAs along with the PIA.
4. Completing a Data Creation Plan

- Data Creation Plans (DCPs) describes the following:
  - Study design (i.e., cohort study, matched cohort study, case-control study, cross-sectional study, etc.)
  - Index event or inclusion criteria, and exclusion criteria
  - Project time frame definitions (i.e., accrual start/end dates, maximum follow-up date, observation window, and lookback window)
  - Main exposure(s) or risk factor(s)
  - Primary and secondary outcome measures
5. Project Kick-off & Completing Data Analysis

- Kick-off meeting occurs once all documents (i.e., PAW, PIA, NDAs, and DCP).

- Introduction to ICES analytic team:
  - Project Manager
  - Analytic Epidemiologist
  - Lead Research Methodologist

- Investigators works closely with the Analytic Epidemiologist to achieve project objectives following kick-off meeting.
6. Submitting manuscript for publication

- Investigators may draft manuscripts while completing data analysis.
- Actions required before manuscript submission:
  - Investigators and Analytic Epidemiologist conduct and document a Re-Identification Risk Assessment.
  - Manuscripts must include specific acknowledgements for each dataset accessed.
- Investigators must inform, and share a manuscript copy with the MOHLTC upon acceptance of publication.
1. Identifying an ICES Scientist
2. Research Ethics Approval
3. Project Activation
4. Data Creation Plan
5. Project Kickoff & Data Analysis
6. Publication

ICES Project Cycle
Q&A Break
ICES Research Programs & Lead Scientists

1. **Cancer**; Rinky Sutradhar, MSc, PhD
2. **Cardiovascular**; Douglas Lee, MD, FRCPC, PhD
3. **Chronic Disease and Pharmacotherapy**; Michael Patterson, MSc
4. **Kidney, Dialysis and Transplantation**; Amit Garg, MD, FRCPC, PhD
5. **Life Stage**; Susan Bronskill, MSc, PhD
6. **Mental Health and Addictions**; Paul Kurdyak, MD, PhD, FRCPC
7. **Populations and Public Health**; Jeff Kwong, MD, MSc, CCFP, FRCPC
8. **Primary Care and Health Systems**; Liisa Jaakkimainen, MD, MSc
Primary Care Questions

• Have primary care reforms (e.g. FHTs) improved healthcare outcomes for patients?
• Does family physician payment model influence provision of preventative care, or quality of diabetes care?
• Is primary care model associated with patient access to care (e.g. reduced emergency department use)?
• Does continuity with family physician improve end-of-life outcomes?
• How is primary care geographically distributed in Ontario?
• Is primary care equitably serving structurally vulnerable populations?
1. Intensity of outpatient physician care in the last year of life: a population-based descriptive study.

Michelle Howard, Abe Hafid, Sarina Isenberg, Amy Hsu, Mary Scott, Katrin Conen, Colleen Webber, Susan Bronskill, James Downar, Peter Tanuseputro. [Accepted for publication by CMAJ Open in Feb. 2021]

Objective:

• To describe outpatient physician care over the last year of life among decedents in Ontario, according to different end-of-life trajectories.

Study Design:

• Retrospective descriptive study of adult decedents (n= 359,559) in Ontario between 2013 and 2017.
Datasets accessed:

- Physician inpatient and ambulatory billing to OHIP.
- Demographic information for all persons eligible to OHIP.
- Demographic, cause-of-death, and place-of-death information for all decedents in Ontario.
- Prescription information for all persons eligible to the Ontario Drug Program.
- Patient-level information for all hospital discharges in Ontario.
- Multiple ICES-derived illness cohorts.
Findings:

- Decedents (n=359,559) experience ~17 outpatient physician encounters in the last year of life; ~9 of which are with family physicians.
- When stratified by end-of-life trajectory, the terminal illness trajectory experienced more encounters and have more physicians involved.

Interpretation:

- Multiple physicians are involved in care in the last 12 months of life for all end-of-life trajectories.
- Family physicians are most intensely involved; highlighting the importance of family physicians as coordinators.
### Figure 2a: Proportion of outpatient physician encounters provided by the top 5 most common specialties and average number of encounters per patient provided by the specialty in last 12 months of life, among decedents who died in Ontario, Canada from 2013 to 2017, per end-of-life trajectory.

#### Terminal Illness
- **Family Medicine**
  - 49.0%, n’encounters = 12.1
- **Medical Oncology**
  - 10.0%, n’encounters = 2.4
- **Internal Medicine**
  - 6.4%, n’encounters = 2.0
- **Therapeutic Radiology**
  - 4.1%, n’encounters = 1.8
- **Haematology**
  - 3.1%, n’encounters = 0.7

#### Organ Failure
- **Family Medicine**
  - 96.4%, n’encounters = 7.7
- **Internal Medicine**
  - 6.0%, n’encounters = 1.1
- **Ophthalmology**
  - 4.4%, n’encounters = 0.5
- **Cardiology**
  - 3.5%, n’encounters = 0.5
- **General Surgery**
  - 2.4%, n’encounters = 0.3

#### Frailty
- **Family Medicine**
  - 99.1%, n’encounters = 19.9
- **Internal Medicine**
  - 7.1%, n’encounters = 0.8
- **Ophthalmology**
  - 4.9%, n’encounters = 0.6
- **Cardiology**
  - 4.4%, n’encounters = 0.5
- **Urology**
  - 2.1%, n’encounters = 0.2

#### Sudden Death
- **Family Medicine**
  - 62.0%, n’encounters = 7.4
- **Psychiatry**
  - 8.4%, n’encounters = 2.0
- **Internal Medicine**
  - 4.8%, n’encounters = 0.6
- **Ophthalmology**
  - 2.9%, n’encounters = 0.3
- **Orthopaedic Surgery**
  - 2.3%, n’encounters = 0.3

#### Other
- **Family Medicine**
  - 54.0%, n’encounters = 7.3
- **Internal Medicine**
  - 7.9%, n’encounters = 1.1
- **Ophthalmology**
  - 4.5%, n’encounters = 0.6
- **Cardiology**
  - 3.2%, n’encounters = 0.4
- **General Surgery**
  - 2.6%, n’encounters = 0.3

#### Overall Cohort
- **Family Medicine**
  - 53.6%, n’encounters = 9.0
- **Internal Medicine**
  - 6.0%, n’encounters = 1.3
- **Medical Oncology**
  - 5.8%, n’encounters = 0.9
- **Therapeutic Radiology**
  - 4.3%, n’encounters = 0.7
- **Ophthalmology**
  - 3.3%, n’encounters = 0.6

### Figure 2b: Proportion of outpatient physician encounters provided by the top 5 most common specialties and average number of encounters per patient provided by the specialty in last 3 months of life, among decedents who died in Ontario, Canada from 2013 to 2017, per end-of-life trajectory.

#### Terminal Illness
- **Family Medicine**
  - 62.0%, n’encounters = 0.2
- **Internal Medicine**
  - 9.7%, n’encounters = 0.8
- **Medical Oncology**
  - 7.0%, n’encounters = 0.5
- **Therapeutic Radiology**
  - 6.4%, n’encounters = 0.6
- **Haematology**
  - 2.3%, n’encounters = 0.2

#### Organ Failure
- **Family Medicine**
  - 99.3%, n’encounters = 2.7
- **Internal Medicine**
  - 9.1%, n’encounters = 0.4
- **Cardiology**
  - 4.3%, n’encounters = 0.2
- **Ophthalmology**
  - 2.0%, n’encounters = 0.1
- **General Surgery**
  - 2.4%, n’encounters = 0.1

#### Frailty
- **Family Medicine**
  - 91.7%, n’encounters = 2.3
- **Internal Medicine**
  - 9.0%, n’encounters = 0.3
- **Cardiology**
  - 4.2%, n’encounters = 0.2
- **Ophthalmology**
  - 2.0%, n’encounters = 0.1
- **General Surgery**
  - 1.0%, n’encounters = 0.1

#### Sudden Death
- **Family Medicine**
  - 88.8%, n’encounters = 2.1
- **Psychiatry**
  - 7.7%, n’encounters = 0.5
- **Internal Medicine**
  - 6.3%, n’encounters = 0.2
- **Orthopaedic Surgery**
  - 2.7%, n’encounters = 0.1
- **General Surgery**
  - 2.6%, n’encounters = 0.1

#### Other
- **Family Medicine**
  - 53.6%, n’encounters = 2.4
- **Internal Medicine**
  - 10.4%, n’encounters = 0.5
- **General Surgery**
  - 2.4%, n’encounters = 0.1
- **Orthopaedic Surgery**
  - 2.6%, n’encounters = 0.1
- **Cardiology**
  - 2.8%, n’encounters = 0.1

#### Overall Cohort
- **Family Medicine**
  - 60.9%, n’encounters = 3.8
- **Internal Medicine**
  - 6.9%, n’encounters = 0.5
- **General Surgery**
  - 4.7%, n’encounters = 0.3
- **Orthopaedic Surgery**
  - 4.2%, n’encounters = 0.3
- **Cardiology**
  - 2.1%, n’encounters = 0.1
2. Does primary care model affect healthcare at the end of life? A population-based retrospective cohort study
Michelle Howard, Mathieu Chalifoux, Peter Tanuseputro. Published in Journal of Palliative Medicine (2017); 20(4).

Objective:
• To examine whether belonging to different models of primary care is associated with end-of-life healthcare use and outcomes.

Study Design:
• Retrospective population cohort study, of decedents who died from April 2010 to March 2013 in Ontario.
2. Does primary care model effect healthcare at the end of life? A population-based retrospective cohort study
Michelle Howard, Mathieu Chalifoux, Peter Tanuseputro. Published in Journal of Palliative Medicine (2017); 20(4).

Datasets accessed:

- Demographic information for all persons eligible to OHIP.
- Individual census data to identify patient neighbourhood income status.
- Patient-level information for all hospital discharges
- Patient-level information for all persons receiving continuing care services in hospitals or LTC homes in Ontario.
- Patient-level information from participating adult inpatient rehabilitation facilities in Ontario.
- Patient-level information from all persons receiving home care in Ontario.
2. Does primary care model effect healthcare at the end of life? A population-based retrospective cohort study
Michelle Howard, Mathieu Chalifoux, Peter Tanuseputro. Published in Journal of Palliative Medicine (2017); 20(4).

Findings:
• Capitation models were more likely to have most physician services provided by a family physician and received more home care service days.
• Decedents from an enhanced fee-for-service model spent significantly more days in an institution compared to those in a capitation model.

Interpretation:
• Decedents in comprehensive primary care models received more care in the community and spent less time in institutions.
<table>
<thead>
<tr>
<th>Reference value</th>
<th>Parameter variable</th>
<th>Parameter estimate</th>
<th>Standard error</th>
<th>p</th>
</tr>
</thead>
<tbody>
<tr>
<td>Ages 70–79</td>
<td>0–49</td>
<td>0.96</td>
<td>0.33</td>
<td>0.0035</td>
</tr>
<tr>
<td></td>
<td>50–59</td>
<td>-0.53</td>
<td>0.28</td>
<td>0.06</td>
</tr>
<tr>
<td></td>
<td>60–69</td>
<td>-0.26</td>
<td>0.24</td>
<td>0.28</td>
</tr>
<tr>
<td></td>
<td>80–89</td>
<td>0.10</td>
<td>0.21</td>
<td>&lt;0.0001</td>
</tr>
<tr>
<td></td>
<td>90+</td>
<td>-1.52</td>
<td>0.27</td>
<td>&lt;0.0001</td>
</tr>
<tr>
<td>Sex—Male</td>
<td>Sex—female</td>
<td>2.04</td>
<td>0.15</td>
<td>&lt;0.0001</td>
</tr>
<tr>
<td>Rurality—urban resident</td>
<td>Rural resident</td>
<td>-0.41</td>
<td>0.22</td>
<td>0.06</td>
</tr>
<tr>
<td></td>
<td>Missing</td>
<td>2.10</td>
<td>2.38</td>
<td>0.38</td>
</tr>
<tr>
<td>Income quintile—lowest</td>
<td>Low</td>
<td>0.003</td>
<td>0.23</td>
<td>0.01</td>
</tr>
<tr>
<td></td>
<td>Middle</td>
<td>-0.97</td>
<td>0.23</td>
<td>&lt;0.0001</td>
</tr>
<tr>
<td></td>
<td>High</td>
<td>-1.23</td>
<td>0.24</td>
<td>&lt;0.0001</td>
</tr>
<tr>
<td></td>
<td>Highest</td>
<td>-1.72</td>
<td>0.24</td>
<td>&lt;0.0001</td>
</tr>
<tr>
<td></td>
<td>Missing</td>
<td>13.29</td>
<td>1.16</td>
<td>&lt;0.0001</td>
</tr>
<tr>
<td>Cancer status—no cancer</td>
<td>Cancer</td>
<td>-0.50</td>
<td>0.16</td>
<td>0.002</td>
</tr>
<tr>
<td>ADG score&lt;sup&gt;a&lt;/sup&gt;</td>
<td>0.75</td>
<td>0.005</td>
<td></td>
<td>&lt;0.0001</td>
</tr>
<tr>
<td>Primary care model&lt;sup&gt;b&lt;/sup&gt;</td>
<td>Enhanced FFS</td>
<td>1.12</td>
<td>0.17</td>
<td>&lt;0.0001</td>
</tr>
<tr>
<td></td>
<td>Traditional FFS</td>
<td>2.21</td>
<td>0.22</td>
<td>&lt;0.0001</td>
</tr>
</tbody>
</table>

<sup>a</sup> Aggregated Diagnosis Groups (indicator of comorbidity).

<sup>b</sup> Primary care models: Capitation—patients are enrolled and the physician is paid mainly by capitation to provide a basket of services to enrolled patients. Enhanced FFS—payment is mainly FFS with incentives for comprehensive care for rostered patients. Traditional FFS—physician payment is FFS with no enhancements, patients are not rostered.
3. MyPractice Reports from Health Quality Ontario

- Collaboration between Health Quality Ontario and ICES, which providers primary care providers quarterly reports generated from health administration.

- Reports measure primary care processes and outcomes:
  - Physician prescribing patterns
  - Patient demographics
  - Case mix

- For more information, please refer to Health Quality Ontario.
Summary

• Using health administrative data is a cost-effective approach for conducting informative population-based research.

• Researchers can collaborate with ICES to produce impactful findings for both knowledge users and policy makers.

• Health administrative data can be used to explore research questions for various healthcare settings and specialties, including primary care.
Questions?

If you have any additional questions or are interested in initiating an ICES project, please reach out to us or directly to ICES McMaster.

Thank you!
Supplementary Slides
# Prominent Data Holdings at ICES

<table>
<thead>
<tr>
<th>Dataset &amp; Source</th>
<th>Purpose</th>
<th>Years Available</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Health Datasets</strong></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Ontario Health Insurance Claims Database (OHIP), MOHLTC</td>
<td>Record all claims by physicians for inpatient and ambulatory visits, consultations, and procedures.</td>
<td>Jul. ‘91 – Feb. ‘21</td>
</tr>
<tr>
<td>Ontario Cancer Registry (OCR), Cancer Care Ontario</td>
<td>Records information about all Ontarians with cancer, including hospital admissions/discharges, clinical diagnoses, consultation and treatment at regional cancer centers, and cause of death information.</td>
<td>Jan. ‘64 – Nov. ‘20</td>
</tr>
<tr>
<td>National Ambulatory Care Reporting System (NACRS), CIHI</td>
<td>Records data for all hospital-based and community-based ambulatory care, such as day surgery, outpatient and community-based clinics, and emergency department visits.</td>
<td>ED: Jul. ’00 – Mar. ‘20 Dialysis/Cancer: Apr. ’03 – Mar. ‘20</td>
</tr>
<tr>
<td>Discharge Abstract Database (DAD), CIHI</td>
<td>Records patient-level information (administrative, clinical, and demographic) on all hospital discharges, including deaths, sign-outs and transfers.</td>
<td>Apr. ‘98 – Mar. ‘20</td>
</tr>
<tr>
<td><strong>Population Datasets</strong></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Ontario Census Area Profiles (CENSUS), StatsCan</td>
<td></td>
<td>‘91, ‘96, ’01, ’06, ’11, ’16</td>
</tr>
<tr>
<td>Registered Persons Database (RPDB), MOHLTC</td>
<td>Records demographic, residence, and vital status information for all persons eligible to receive OHIP.</td>
<td>Apr. ’91 – Jan. ’21</td>
</tr>
</tbody>
</table>
# Prominent ICES-derived Data Holdings

<table>
<thead>
<tr>
<th>Dataset</th>
<th>Purpose</th>
<th>Years Available</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Health Datasets</strong></td>
<td></td>
<td></td>
</tr>
<tr>
<td><strong>Primary Care Population (PCPOP)</strong></td>
<td>Records population-level data on all people (eligible to OHIP), such as primary care roster status, access to specialty care, continuity of care and models of care.</td>
<td>Apr. ’95 – Apr. ‘20</td>
</tr>
<tr>
<td><strong>Linked Delivering Mother and Newborns (MOMBABY)</strong></td>
<td>Links inpatient admission records of delivering mothers and their newborns.</td>
<td>Apr. ’88 – Mar. ‘20</td>
</tr>
<tr>
<td><strong>Illness-specific cohort datasets</strong></td>
<td>Validated cohorts of individuals with specific illnesses (i.e., Asthma, CHF, COPD, Diabetes, Dementia, etc.)</td>
<td>Prevalence: Apr. ’91 – Mar. ‘19 Incidence: Apr. ’96 – Mar ‘19</td>
</tr>
</tbody>
</table>

For more information about all data holdings available at ICES, please refer to the [ICES Data Dictionary](#).