

Exciting Research Opportunities Using Administrative Data



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The logo for SickKids, with the word 'SickKids' in a blue, sans-serif font.

Outline

- ICES
- Data
- Exciting new areas

What is ICES?

ICES = Institute for Clinical Evaluative Sciences

- Independent
- Non-profit organization
- Prescribed entity under Ontario privacy legislation
- Funded by Ontario MoHLTC core funding and peer-reviewed research grants

ICES Mission

Our mission is research excellence resulting in trusted evidence that makes policy better, health care stronger and people healthier.

Expanding Partnership with Ontario's Leading Health Institutes

ICES North
In Development

ICES uOttawa
Opened in 2010

LAKE HURON

ICES Central opened in 1992 on the campus of Sunnybrook Health Sciences Centre in Toronto

ICES

ICES Queen's
Opened in 2007

LAKE ONTARIO

ICES UofT
Opened in 2012

ICES Western
Opened in 2012

ICES McMaster
In Development



Researchers use a secure portal for access to ICES data holdings.

What makes ICES unique?

Data - Ability to link at the individual level health-related information from a variety of independent data sources such as:

- Health services datasets
- Clinical registries
- Population-based health surveys
- Care provider datasets
- Electronic medical records



ICES Data Holdings

Health Services

OHIP Physician Claims
ON Case Costing Initiative
ON Drug Benefit Claims
ON Home Care Admin System
ON Mental Health Reporting System
On Trauma Registry Pilot Data
Continuing Care Reporting System (Chronic Care)
Canadian Organ Replacement Register
Client Profile Database (LTC home application/placement)
Discharge Abstract Database
OHIP Emergency Claims Database
Home Care Database
HOBIC (Health Outcomes for Better Information and Care)
Levels of Care Classification System
National Ambulatory Care Reporting System
National Rehab System
interRAI Contact Assessment
Resident Assessment Instrument – Home Care
Same day surgery database
Electronic Health Records

ICES Derived Cohorts

Asthma
Congestive Heart Failure
Chronic Obstructive Pulmonary Disease
HIV-positive cohort
Hypertension
MOM/baby
Ontario Diabetes Data
Acute Myocardial Infarction
Paediatric Inflammatory Bowel Disease
Ontario Multi-specialty Physician Networks

Restricted Registries*

Cardiac Care Network Data
Implantable Defibrillator Database
CT/MRI Abstracted Data
Enhanced Feedback for Effective Cardiac Treatment (EFFECT)
Ontario Breast Screening Program – CCO
Ontario Cancer Registry – CCO
Ontario Stroke Registry
Cytobase – CCO
New Drug Funding – CCO
Developmental Disabilities
DMAR
Métis Citizenship Registry
Linked electronic health records

* Access restricted to specific users according to data sharing agreement

In Development or Negotiation

Negotiated – being Linked
Vital Stats Death Register
Citizen and Immigration Canada (ON data)
Indian Registry System file (Ontario)
BORN (collaborative access)
Ontario HIV Treatment Network (restricted access)

Under Negotiation
Child and Youth Health Linkable and De-identified Repository (includes data from Ministry of Education, Child and Youth Services, Ministry of Comm. and Social Services, Comm. Agencies
DATIS (Drug and Alcohol Treatment Information System)

What makes ICES unique?

People - ICES scientists and data experts are internationally recognized leaders;

- many are practicing clinicians who understand health care delivery.
- multidisciplinary teams expert in the use, protection and translation of this data into discoveries and policy impact



Core Administrative Health Data

Collected by hospitals, health care providers & government:

- Discharge abstract database
- National ambulatory care reporting system
- Ontario Health Insurance Plan
- Ontario Drug Benefit Program
- Home care
- Registered persons data base

- Others...

ICES Data Repository is globally unique in scope and breadth

- **Individual level:** reflects people and their health care experiences
- **Linkable:** once linked, provide information about continuity of care
- **Longitudinal:** most health care records over time since 1991
- **Population based:** health records of 13 million people in 2012, four million Electronic Medical Records profiling 330,000 Ontarians
- **Breadth of services:** most publicly funded health services, some services outside health
- **De-identified:** unique ICES Key Number – encrypted health card number
- **Secure and Privacy Protected:** approved by Office of the Information and Privacy Commissioner



Validated Cohorts

- Diabetes
- Asthma
- Hypertension
- Stroke
- Acute MI
- Congestive Heart Failure
- Inflammatory Bowel Disease
- Schizophrenia

Linkage

- Clinical registries (cancer, ICD, stroke) or research data
- Surveys
- Demographic
 - Registered Person Data
 - Vital Statistics (Death File only)
 - Citizenship and Immigration Canada
 - First Nations
- Family data -- MOMBABY

Routinely Collected Biomarkers

BORN Ontario

- prenatal and newborn screening data

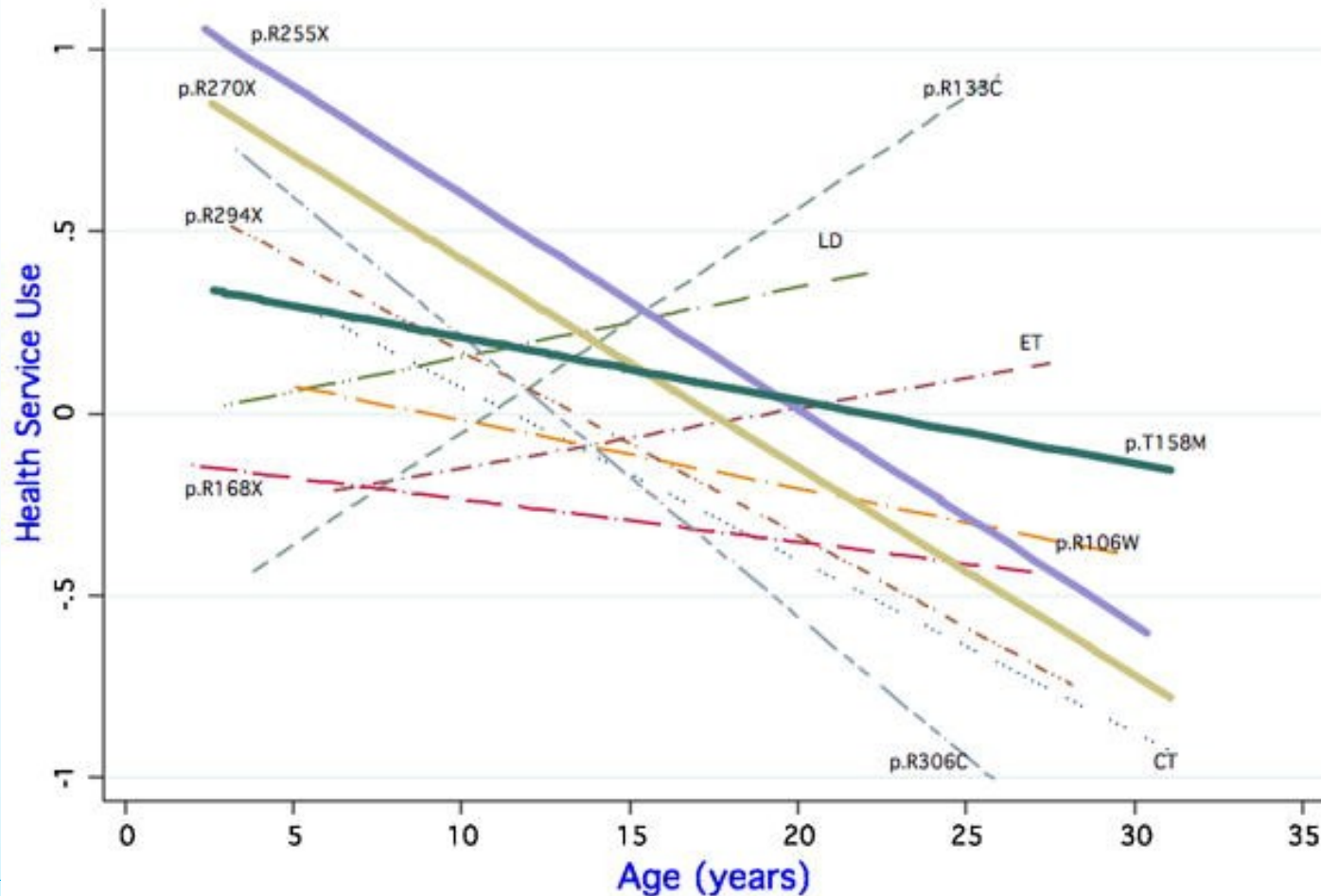
Cancer registries

- Genetic and other risk bio-markers through chart abstraction

Ontario Lab Information System

Genotype-Phenotype -- Rett Syndrome

Young D et al. Res Autism Spectr Disord. 2011 JANUARY-MARCH; 5(1): 442-449.
doi: 10.1016/j.rasd.2010.06.007



New Directions

Routine data from other ministries

- Education
- Community and Social Services
- Children and Youth Services

Opportunities

- Linkage studies □ efficient follow up
 - Outcome data evolving
- Population-based comparison groups
- Intersection of biological/social risks (longitudinal) on health outcomes

Exposure *(Experience)*

Epigenome

Biochemical /Biophysical Pathway

Phenotype

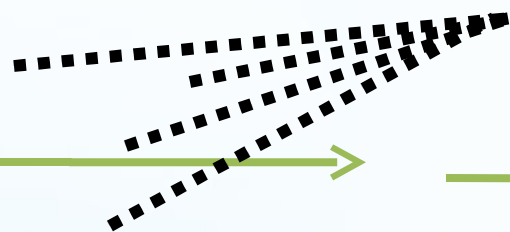
(Prenatal)
Maternal
Smoking



Childhood
Abuse



Childhood
SES

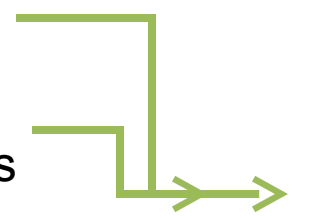


Exposure Specific
Pathways

Common Pathways

Exposure Specific
Pathways

Exposure Specific
Pathways



OUTCOMES

Thank you! Questions?



open We'd like to open the floor to shorter speeches disguised as questions. *Yes dis*