

# **INTÉGRATION ET UTILISATION DE DONNÉES MÉDICOADMINISTRATIVES A ICES**



**Journée scientifique de l'Alliance santé Québec**

---

**Michael Schull, MD, MSc, FRCPC**  
**December 3, 2014**

---

# ICES Context

---

- 22 year history, Canada's largest health services research institute.
- Independent, not-for-profit research institute
- We act as a independent steward for Ontario's holdings of individual-level, de-identified and linkable health and health-related data
- 185 scientists; 130 staff; 5 physical locations across Ontario with expertise in using linked data sets to generate new knowledge that directly informs health system decision making and policy



Data  
Discovery  
Better Health

## MISSION:

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

# 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
- Custom ad-hoc data linkages



**People** - ICES scientists and data experts are internationally recognized leaders; many are practicing clinicians who understand health care delivery. They work with multidisciplinary teams at ICES comprising experts in the use, protection and translation of this data

---

# ICES Data Repository ranks globally in scope and breadth

---

- Individual level: reflects people and their health care experiences
- Longitudinal: most health care records over time since 1991
- Population based: health records of 13 million people in 2012, linked primary care EMRs for 800,000 Ontarians
- Breadth of services: most publicly funded health services, some services outside health
- De-identified: unique ICES Key Number – encrypted health card number
- Linkable: once linked, provide information about continuity of care
- Secure and Privacy Protected: legislated status, approved by Office of the Information and Privacy Commissioner

---

# ICES Capabilities

---

- Wide variety of data partnerships within and beyond health
- Data management and integration expertise
- Expert data users – scientists and analysts
- Trusted privacy and security policies and systems
- ICES can receive and use personal health information as a Prescribed Entity under Ontario's Personal Health Information Protection Act (PHIPA)
- Tremendous expertise in privacy, de-identification and secure linkage

# Some ICES Key Data Partners

---

- **Ontario Health sector:**

- Ministry of Health and Long Term Care– most admin data
- Cancer Care Ontario; Cardiac Care Network
- POGO; BORN
- CIHI
- Ontario Association of CCACs
- Ontario Coroner's Office
- Hospitals, physicians (EMRs), researchers
- Public Health Ontario
- Children's Mental Health – Kinark

- **Other Ontario sectors:**

- Ministries of Community and Social Services, Education, Transportation,

- **Aboriginal population (Ontario);**

- Metis Nation (Ontario), Chiefs of Ontario

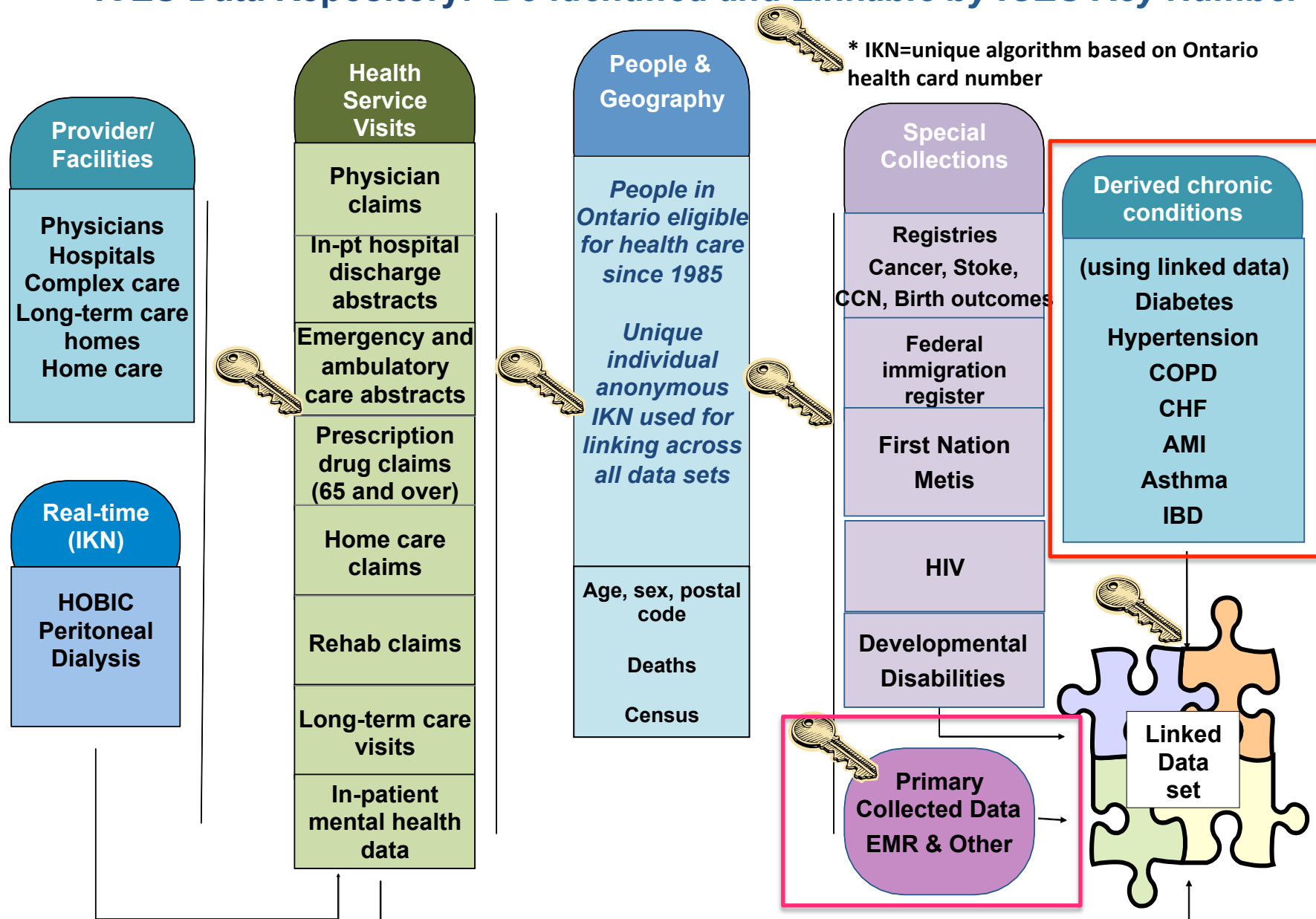
- **Federal:**

- Citizenship and Immigration Canada
- Statistics Canada
- AANDC – Federal First Nations Register
- Correctional Services Canada

- **Emerging:**

- Ontario Health Study
- Ontario Brain Institute

# ICES Data Repository: *De-identified and Linkable by ICES Key Number\**





# Key ICES activities

---

- Investigator initiated research in 7 research programs (cardiac, cancer, primary care/pop health, health system, chronic disease/pharmaco, mental health and addictions, renal disease)
- Grey literature reports in response to “Applied Health Research Questions” from health system stakeholders
- Ontario SPOR Support Unit Data Platform, creating linked de-identified datasets for Ontario (and soon all Canadian) researchers
- Ensuring high quality data and information management, development of new analytic methods, and expanding data holdings

---

# ICES Data and Analytic Services

## Ontario SPOR Support Unit (OSSU)

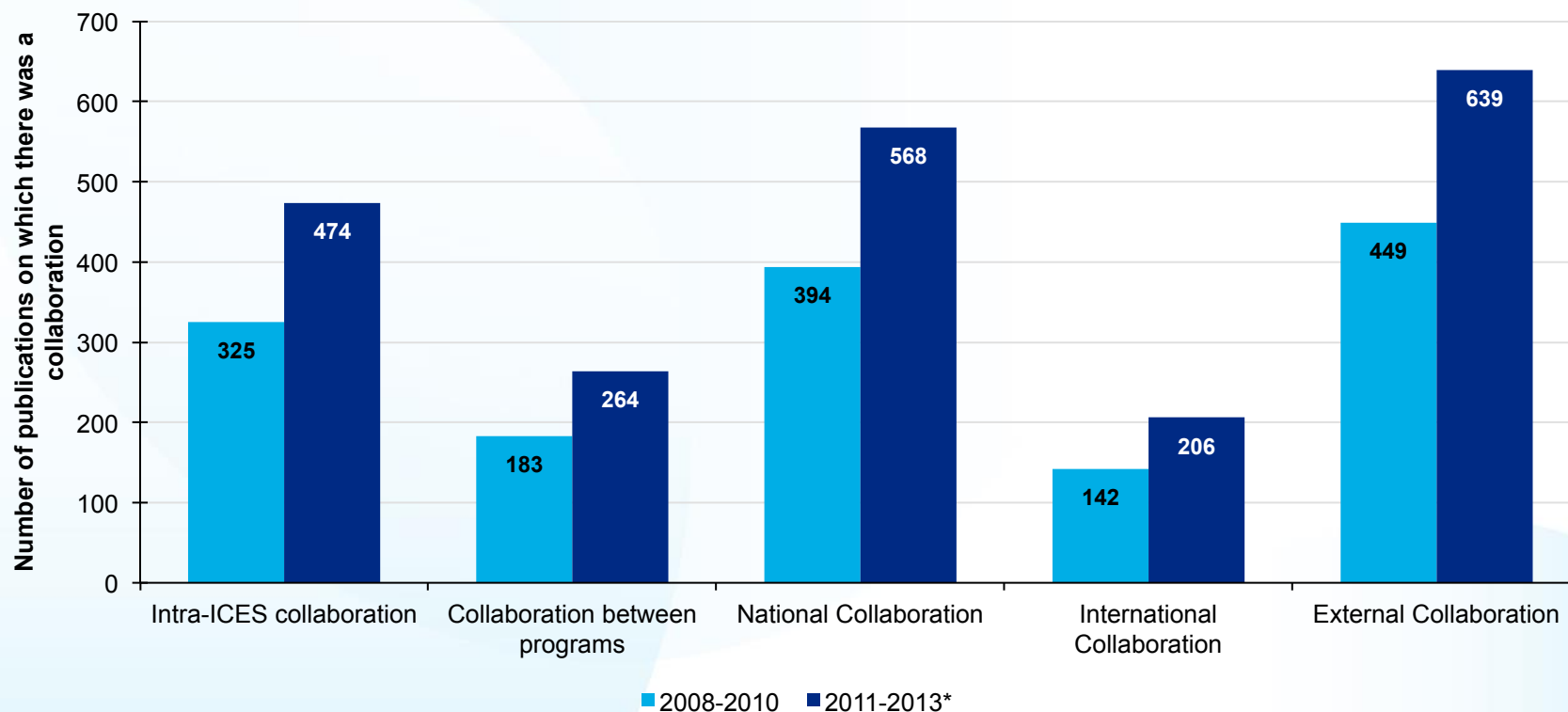
---

- As a key contributor to the CIHR SPOR\*, the OSSU will link up research and implementation strengths across the Ontario to produce positive impacts for patients, researchers, health care practitioners, policy makers and other stakeholders within a five year time frame
- Under OSSU, CIHR and the Ontario government will make major investments in ICES to:
  1. Enhance ICES' data platform
  2. Increase access to ICES data

\* More detail about Canadian Institutes of Health Research (CIHR) Strategy for Patient-Oriented Research (SPOR) and SPOR SUPPORT Units is available at: <http://www.cihr-irsc.gc.ca/e/46264.html>

## Research Capacity: Research Collaborations

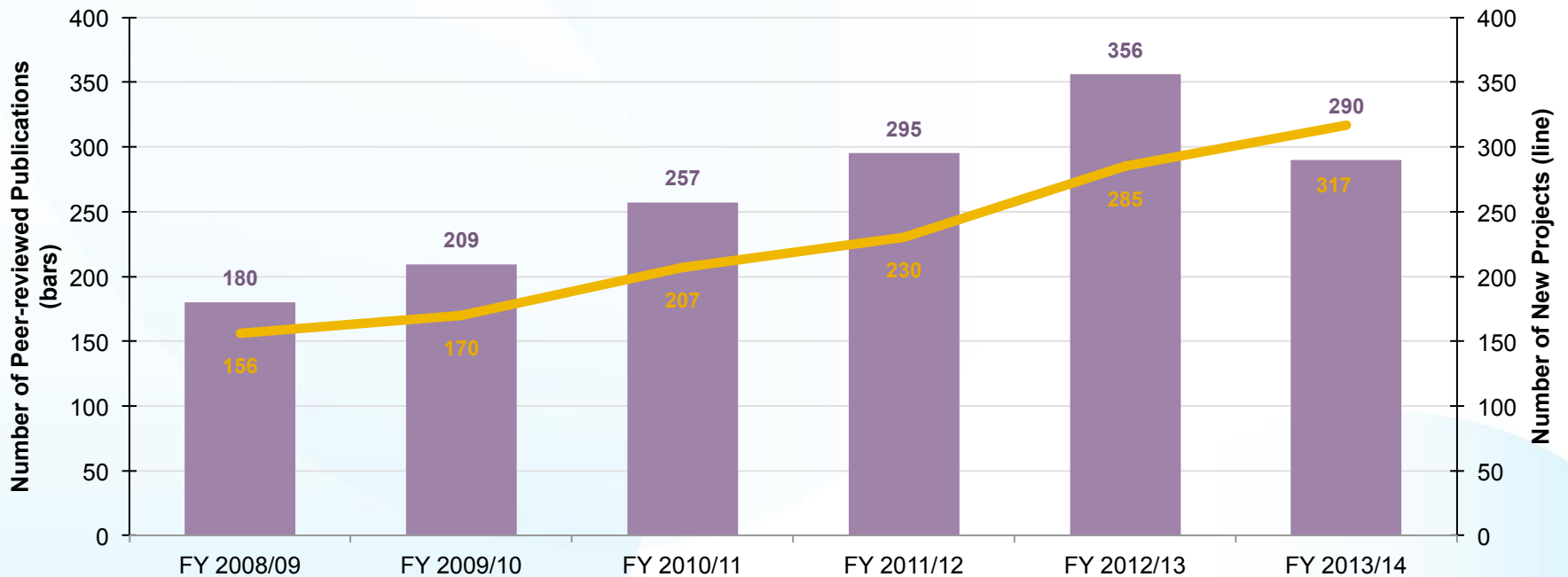
### Collaboration on Publications (2008-2010, 2011-2013)



- ICES scientists collaborate most often with those external to ICES (87% of publications between 2011-2013) and on a national level (77% of publications between 2011-2013).

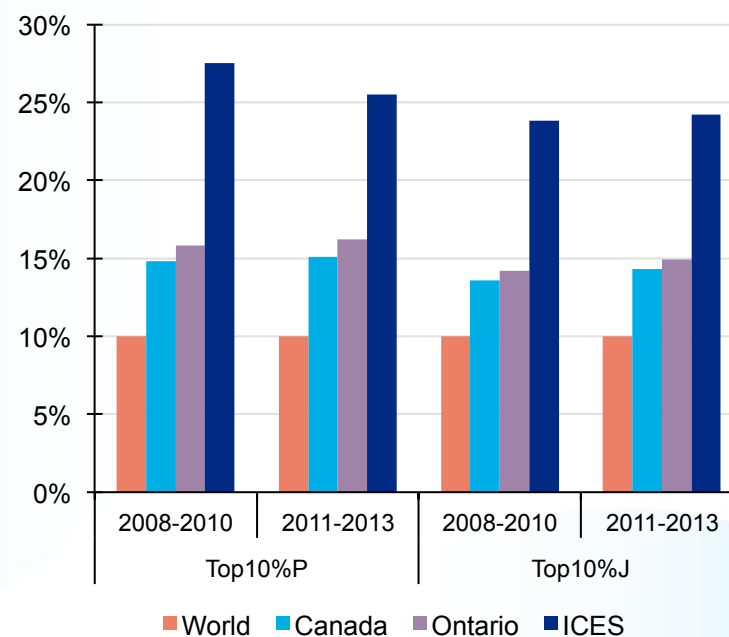
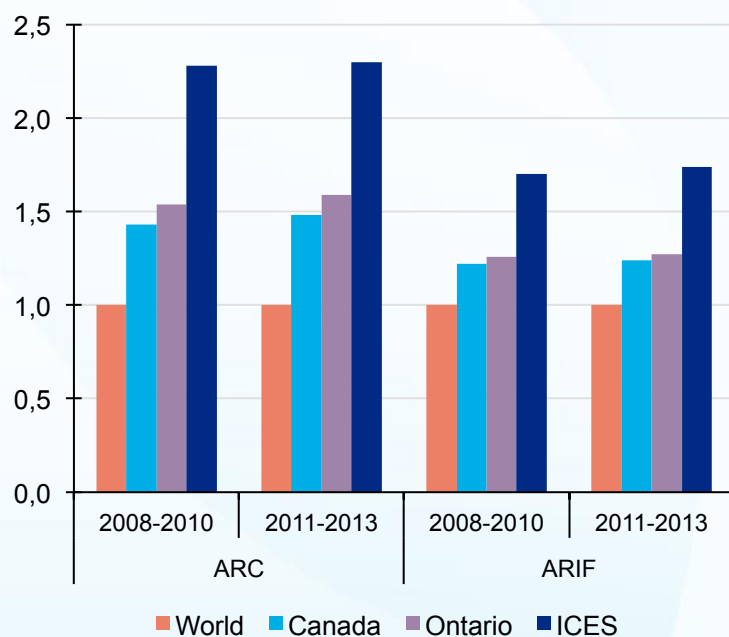
## Knowledge Generation: Research Quantity

### Publications and New Projects (2008/09-2013/14)



# Knowledge Generation: Research Quality

## Impact and Quality of Publications (2008-2011, 2011-2013)



- The quality and impact of ICES publications, as measured by ARC, ARIF, Top10%P and Top10%J, continues to be strong and continues to score higher than comparator jurisdictions.

# Impact on Policy and Practice

## High Impact ICES Projects, Collaborations (2013/14)

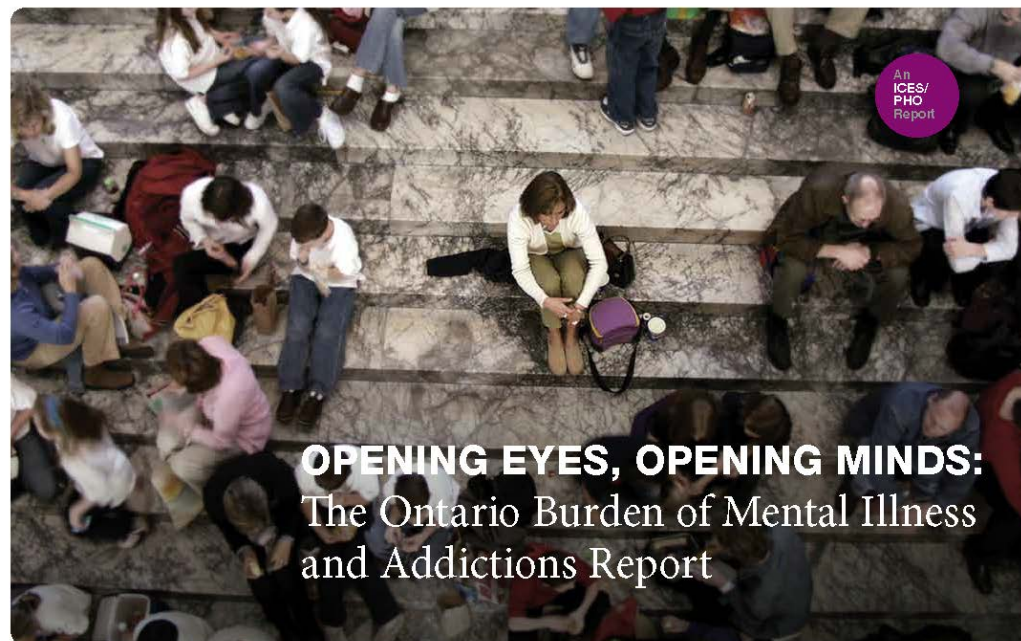
### High Impact ICES Projects

<i><b>Title</b></i>	<i><b>ICES Lead(s)</b></i>	<i><b>External Stakeholder</b></i>
Indicators of primary care provided to persons with developmental disabilities in Ontario	<b>Yona Lunskey</b> (ICES Scientist)	Ontario Ministry of Community and Social Services
Emergency room failure mortality risk grade (EHMRG) calculation	<b>Douglas Lee</b> (ICES Scientist)	Peter Munk Cardiac Centre, University Health Network
Physician's warning for unfit drivers and the risk of trauma from road crashes	<b>Don Redelmeier</b> (ICES Scientist)	Office of the Ontario Ombudsman
Ontario Physician Networks	<b>Therese Stukel</b> (ICES Scientist); co-investigator, <b>Rick Glazier</b> (ICES Scientist)	Ontario Ministry of Health and Long-Term Care; not available for comment

### High Impact ICES Collaborations

<i><b>Title</b></i>	<i><b>ICES Lead(s)</b></i>	<i><b>External Stakeholder</b></i>
Citizen and Immigration Canada data partnership	<b>Karey Iron</b> (Director, Data Partnerships and Development)	Citizen and Immigration Canada
Ontario Stoke Evaluation Program	<b>Ruth Hall</b> (ICES Scientist); co-investigator <b>Moir Kapral</b> (ICES Scientist)	Physician, Kingston General Hospital
Canadian Network for Observational Drug Effect Studies (CNODES)	<b>David Henry</b> (ICES Scientist, CNODES Co-Principal Investigator); <b>Mike Paterson</b> (ICES Scientist, CNODES Ontario Site Lead)	Health Canada, Controlled Substances and Tobacco Directorate

# ICES Reports



OCTOBER 2012

**ICES** Institute for Clinical  
Evaluative Sciences  
Twenty Years • 1992-2012

**Public Health  
Ontario**  
PARTNER FOR HEALTH

**Santé  
publique  
Ontario**  
PARTENAIRES POUR LA SANTÉ

Knowledge Translation Reports  
March 2012

## CHRONIC DISEASES

in the *Métis Nation of Ontario*

Chronic Disease Surveillance Program  
*Métis Nation of Ontario*

# Latest ICES Publications



Reviews progress made in the provision of stroke care across Ontario and compares variations across the 14 Local Health Integration Networks.

Nov 2014



# Latest ICES Publications

Describes burden of four health behaviours—smoking, unhealthy alcohol consumption, poor diet and physical inactivity—and the impact on Ontario hospitals

May 2014



# ICES data in action: life expectancy web calculator

**BiG**  
**LIFE**

**Health**  
**Calculators**

Calculators

More

What would you like us to calculate for you?

☒ Life Expectancy

☐ Future Hospital Use

ABOUT YOU

Age: 50 (between 20 and 79 years)

Sex

☒ Male

☐ Female

Height: 188 cm or 6' 2"

Weight: 91 kg or 200 pounds

HEALTH BEHAVIOURS

Smoking Status

What is your smoking status?

☐ Current heavy smoker (a pack or more a day)

☐ Current light smoker (less than a pack a day)

☐ Former heavy smoker (a pack or more a day)

☐ Former light smoker (less than a pack a day)

☒ Never smoker

Alcohol Consumption

How often do you consume alcoholic beverages?

☒ 1 or more times per month

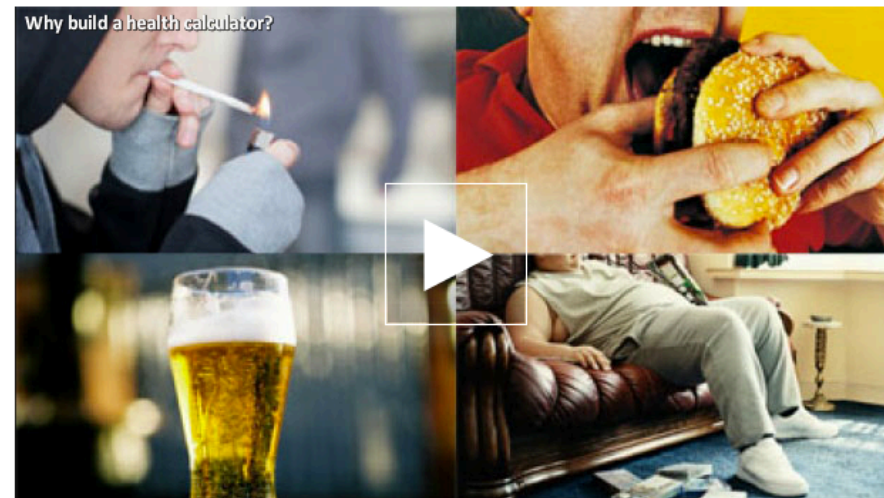
<http://www.projectbiglife.ca/>

- Dinosaur discoveries
- Death, denial in North
- Vaccine myths busted
- My racism experiences

## UPDATED | Hospitalization calculator tallies Ontarians' health risk

4 unhealthy habits blamed for sending Ontarians to hospital more than 900,000 days a year

By Matt Kwong, CBC News Posted: May 29, 2014 5:00 AM ET | Last Updated: May 29, 2014 10:16 AM ET



Why build a health calculator? 5:34



Calculator tallies Ontarians'

If a shortened lifespan doesn't scare you into dropping some unhealthy habits, maybe the prospect of a lengthy hospital stay will.

That's the thinking behind new online tools developed by the Institute for Clinical Evaluative Sciences and the Ottawa Hospital Research Institute. The researchers launched a "future hospital use" calculator today that

### Stay Connected with CBC News



ADVERTISEMENT



### Top News Headlines



- Canadian woman reportedly seized by ISIS in Syria

>1 Million hits in first 2 weeks

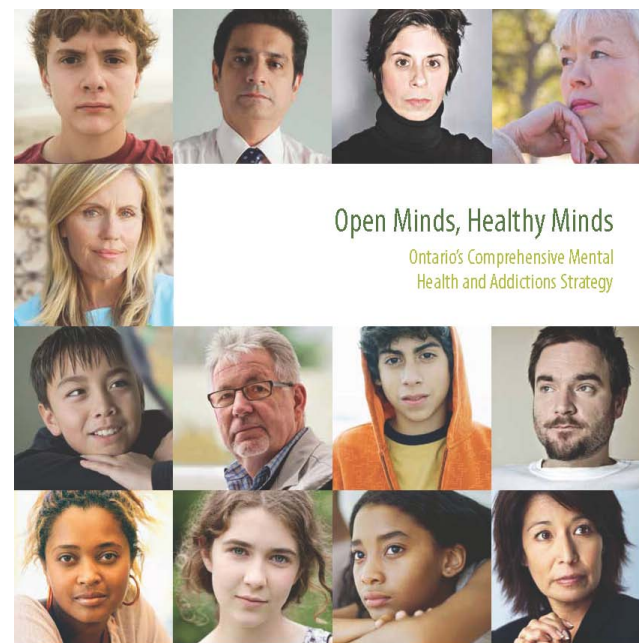
# Looking ahead: adding non-health administrative data...

ICES has a leading role in evaluating the Ontario Comprehensive Mental Health and Addictions Strategy



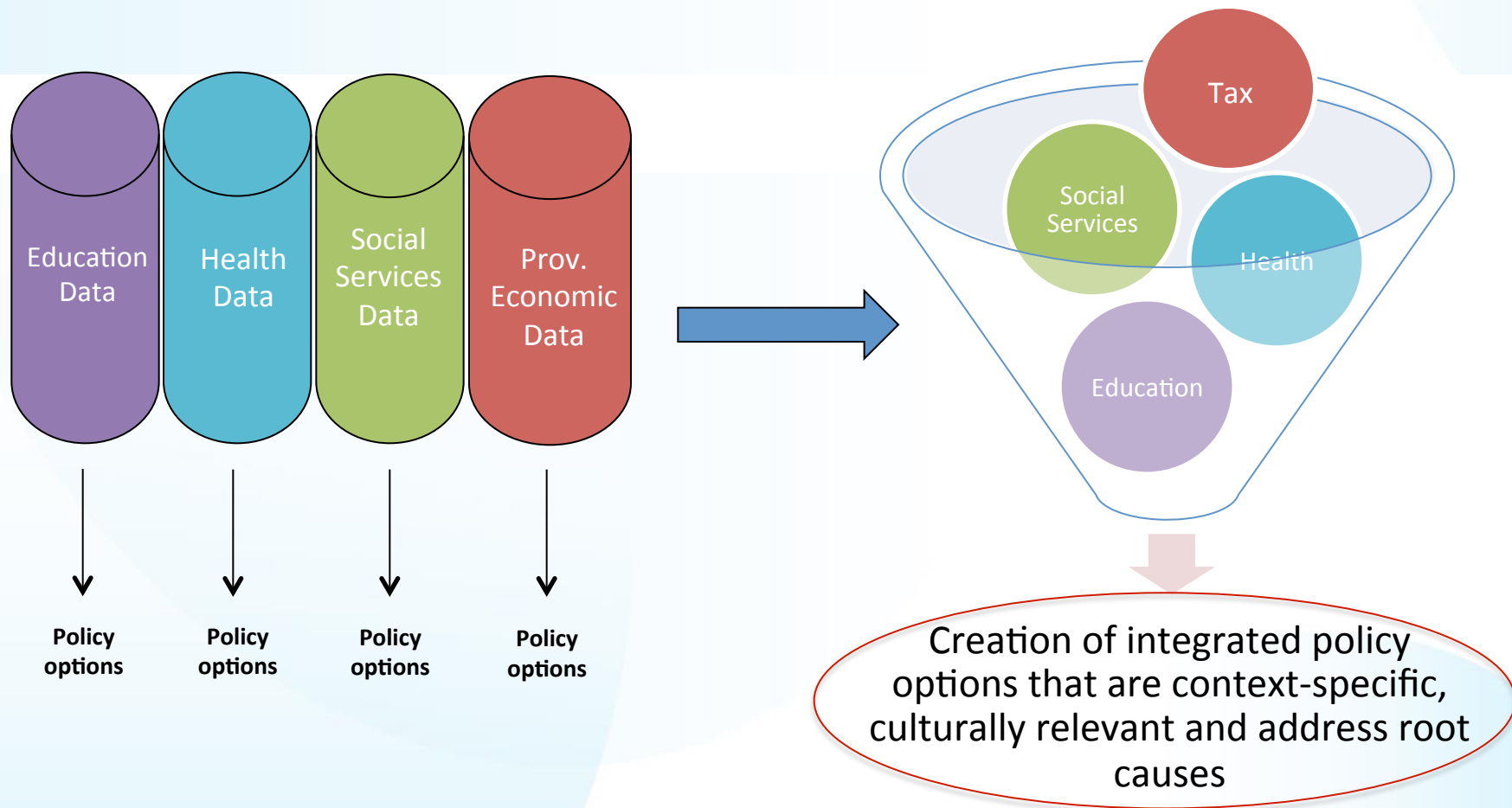
## Ontario Inter-ministerial Working Group

- Ministry of Health and Long-Term Care + 15 other Ministries



# Looking ahead:

## *An “integrated story” to identify the right policy options*



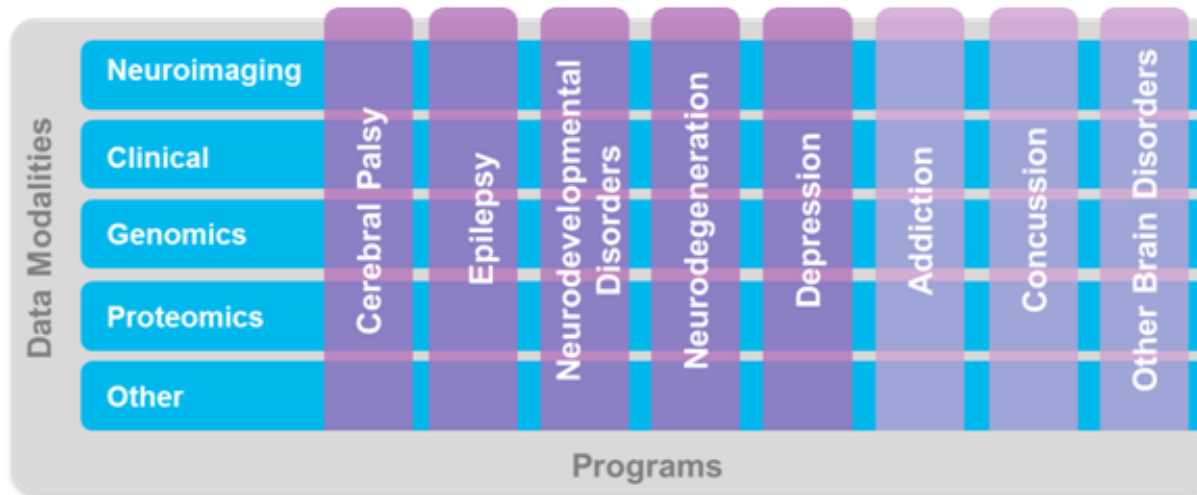
Reproduced in part from Ministry of Health and Long-term Care  
2014, with permission

# Looking ahead

## Linking detailed lifestyle, risk factor, biologic and genomic data:

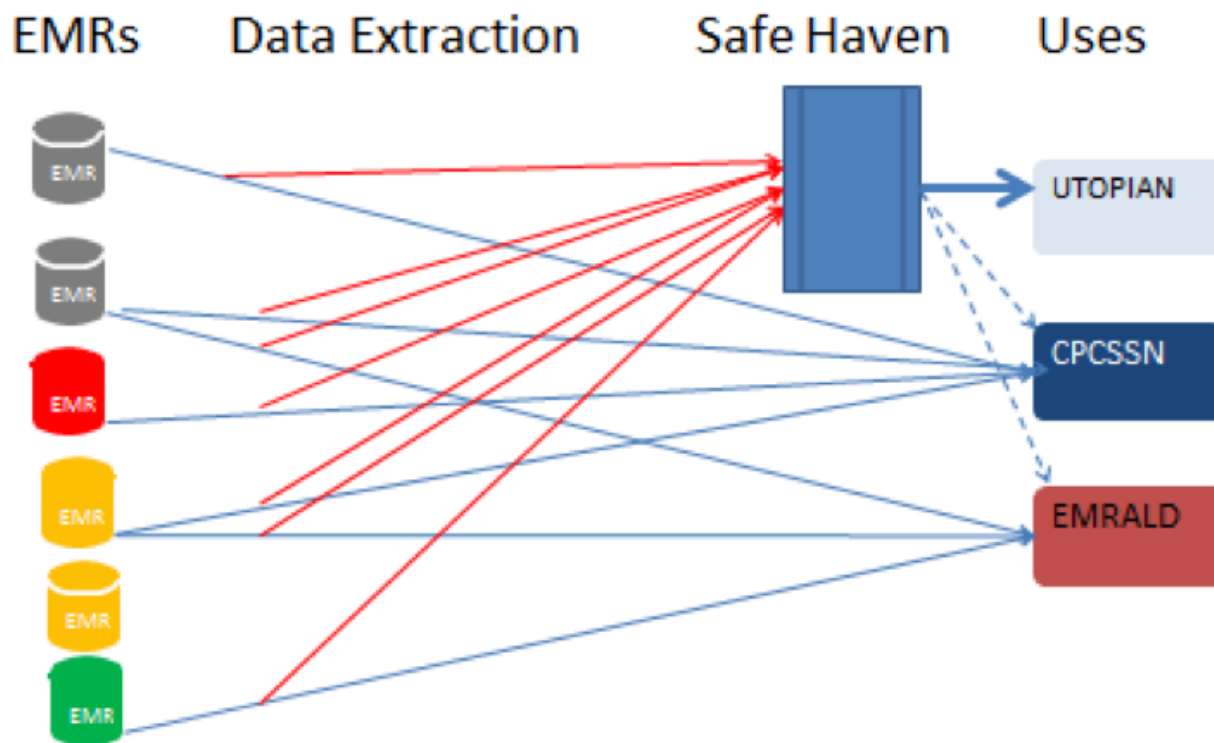
- Ontario Health Study,
- Ontario Brain Institute (OBI)
- Others...

### OBI BRAIN-CODE



# Looking ahead

## Expanding linked EMR data



---

# Challenges

---

- **Data (broad but not deep, timeliness variable)**
- **Administrative data collected by other parties, need for ongoing, careful validation and quality checks**
- **Substantial quantitative expertise, more limited expertise in qualitative research, health economics, we rely on collaboration/partnerships**
- **Increasing expectations re privacy/security**
- **Constraints on cross-jurisdictional data sharing and/or analysis**



**MERCI**

