The Future of Health Data Accessibility in Canada

Tuesday, October 18, 2016

MaRS Discovery District, Toronto

This session was generously sponsored by Pfizer Canada Inc.

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Session Overview

The Data Liberation Initiative (DLI), a partnership between Statistics Canada and post-secondary institutions, was one of the first attempts to ensure affordable and equitable access to national microdata files, databases and geography files collected by Statistics Canada. However, various database agencies have started collaborating with public and/or private stakeholders. This session seeks to address the challenges and successes associated with health data accessibility in Canada as well as comparisons with other countries.

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Who has data?

- Provinces
- Provincial Agencies
- Private Insurers
- Private Companies
- Patient Societies
- Patient Registries

Types of Health Data

- Available
  - Diseases, Comorbidities
  - Severities
  - Health System Resource Utilization
  - Indicators-wait times
  - Patient Reported Outcomes (PROMs), Patient Reported Experience Measures (PREMs)
- Less Available
  - Out of Pocket Resources
  - Private Insurer Resources

Open Data Directive

Ontario is committed to being the most **open** and transparent government in Canada. The new **Open Data Directive** maximizes access to government **data** by requiring all **data** to be made public on the **Ontario Data** Catalogue, unless it is exempt for legal, privacy, security, confidentiality or commercially-sensitive reasons. Nov 27, 2015.

Ontario's Open Data Directive maximizes access to government data by requiring all data to be made public, unless it is exempt for legal, privacy, security, confidentiality or commercially-sensitive reasons. It sets out key principles and requirements for publishing open data, and applies to data created and managed by Ontario ministries and provincial agencies.

Questions to Think About

- Who and where are the data custodians?
- Who are the people involved with accessing health data?
- What are the current roadblocks being experienced when accessing health data?
- What are the successes associated with accessing health data?
- What are the legal/privacy implications when accessing health data?
- What are the costs associated with accessing health data?
- What are the implications after health data has been accessed policy-wise?
- What happens to the data afterwards?

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Meet the Panel

Moderator:

- Nicole Mittmann (CCO and SRI)

Speakers:

- Janey Shin (Janssen Canada Inc.)
- Ximena Camacho (ICES)
- Steven O’Reilly (CIHI)

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Speaker 1: Janey Shin

Janey Shin is the Director, Real World Evidence at Janssen Inc. in Canada. She is responsible for developing the Janssen RWE strategy for Canada and for driving high priority evidence research projects through partnerships with healthcare, government, academic, research, and data provider organizations.

Prior to Janssen, Janey was the Director of Medical Affairs at Johnson & Johnson Medical Companies (JJMC) Canada, where she lead the development and execution of Medical Education, Clinical Affairs, Health Economics and Market Access, and Medical Information strategies across all franchise portfolio of medical device products.

Prior to Johnson & Johnson, she was the Director of Analytics and Surveillance at the Canadian Partnership Against Cancer and was responsible for driving key oncology pan-Canadian initiatives, including enhancing surveillance systems, developing health economic system decision-making tools, and building analytic capacity through engagement and partnerships with federal, provincial, and territorial stakeholders.

Over the last two decades, Janey has had progressive roles in statistics, clinical operations, sales and marketing operations, and Lean Six Sigma. Janey holds an MBA from the Rotman School of Management and a Masters in Biostatistics, both from the University of Toronto.

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Speaker 2: Ximena Camacho

Ximena has been with the Institute for Clinical Evaluative Sciences (ICES) since 2008 and has worked in a variety of research areas, including aging, cancer, and drug policy. Ximena is currently the Director of the Data and Analytic Services department at ICES, which supports access to data for non-ICES researchers and Ontario health system stakeholders.

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Speaker 3: Steven O'Reilly

As Executive Director/Associate CIO, Steve is responsible for leading the Integrated e-Reporting initiative and the Portal Services program at CIHI. His portfolio also includes a leadership role within the Information Technology and Services Division for both Digital Strategy and Integration Services.

With more than 25 years of experience in the health sector, Steve has extensive knowledge of health information and health information systems. Prior to joining CIHI, he served as chief executive officer of the Newfoundland and Labrador Centre for Health Information. He did foundational work with the Newfoundland and Labrador Health System Information Task Force and was an early proponent of the electronic health record.

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The present+future of health data accessibility in Canada
A Perspective from Industry

Janey Shin, Director, Real World Evidence
Government Affairs and Market Access

Gwendolyn Ryals, *Look at Me*
Artwork from The Creative Center

CAPT Symposium
October 2016

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RWE has reached a tipping point due to increasing demand to data, and stakeholders are responding

Patients

- Interest in real-world evidence mixed with questions on data privacy
- Starting to "create" real-world data via forums

QSR WebMD patientslikeme

HTA Bodies

- Broad variation of use, some systematic (e.g. UK, Italy) others more research focused (e.g., US)

NHS IQWiG CADTH INESSS

Payers

- Selected payers use RWE for formulary decisions (US)
  Emerging outcomes based/risk-sharing contracts

CMS UnitedHealth Group

Regulators

- Mainly focused on pharmacovigilance
- Adaptive licensing concepts and corresponding use of RWE data

FDA Health Canada Santé Canada emea SFDA

Academia

- Broad use of RWE as source of insight to medical research
- Partnerships with other stakeholders

University of Alberta Cochrane Collaboration Yale School of Medicine

Providers/Clinicians

- Usage of internal RWE datasets for cost/quality monitoring and physician incentives
- Creating registries to generate RWE
- Disease-based EMRs

Data accessibility today for industry researchers can be complex

Data access options:

1. Formal data request to provincial sources (if non-prohibited) either directly or indirectly

2. Formal data request to medical databases (disease-based, EMR networks)

3. Supporting research through Investigator Initiated Studies

Collaborations: There is a cultural shift towards improved data access with proper governance

Opportunities and Benefits

- Improve data quality and efficiency
  - Data interrogation
  - Efficient and transparent
- Improve understanding of outcomes in real-world settings
  - Improves insights in health system delivery leading to better patient outcomes
  - Advanced analytics and methodology capabilities
  - Reproducibility of research (eg OHDSI)
- Engagement and robust discussions with all stakeholders
  - Public/private partnerships
  - Building trust

Data Accessibility in Canada is Evolving in a Positive Direction BUT it still has challenges

- Limited transparency about the process for data access
- Variable cycle times for obtaining data
- Approval requirements
- Inter-provincial data sharing
- Reporting of Adverse events for secondary data vs primary data

Where do we go from here?

- ✓ Continue collaborative efforts between the private and public sector
- ✓ Break down silos that prevent innovation
- ✓ Increased utilization of data will drive healthcare and “big data” solutions

Thank you

Contact information:
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October 18, 2016

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Increasing Access to Data with ICES Data & Analytic Services (DAS)

XIMENA CAMACHO

CAPT – OCTOBER 18, 2016

Overview

1. **Background**
2. **ICES Data & Analytic Services (DAS)**
3. **Public Perspectives**
4. **DAS Private Sector**
5. **Conclusions**
6. **Acknowledgments**

The Institute for Clinical Evaluative Sciences

- **Independent, non-profit research institution established in 1992**
- **Population-based health research**
- **Evaluation of health care delivery and outcomes**
- **Prescribed Entity status (PHIPA s.45)**
- **200+ scientists across 6 sites in Ontario**

ICES Data Repository

- **Health services utilization**
- **Clinical registries**
- **Population-based health surveys**
- **Care providers**
- **Electronic Medical Records**

Life Expectancy and Unhealthy Behaviours

BiG LiFE Health Calculators

Calculators | More

Updated life expectancy calculator. Based on findings from a new study published in PLoS Medicine.

PLOS | MEDICINE

RESEARCH ARTICLE

Measuring Burden of Unhealthy Behaviours Using a Multivariable Predictive Approach: Life Expectancy Lost in Canada Attributable to Smoking, Alcohol, Physical Inactivity, and Diet

Douglas G. Manuel[1,2,3,4,5,6,7]*, Richard Perez[1,2,5], Claudia Sanmartin[3], Monica Taljaard[1,5], Deirdre Hennessy[1,3], Kumanan Wilson[1], Peter Tanuseputro[1,2,6], Heather Manson[7], Carol Bennett[1,2], Meltem Tuna[1,2], Stacey Fisher[1,5], Laura C. Rosella[2,7,8]

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CrossMark click for updates

OPEN ACCESS

Opioids

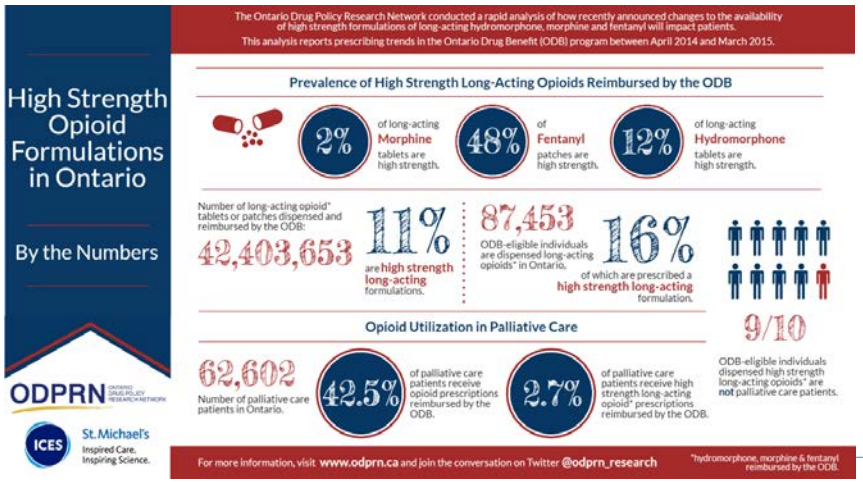
Research

Trends in high-dose opioid prescribing in Canada

Tara Gomes MHSc Muhammad M. Mamdani PharmD MA MPH J. Michael Paterson MSc
Irfan A. Dhalla MD MSc David N. Juurlink MD PhD

Opioid prescribing is a surrogate for inadequate pain management resources

Hillel M. Finestone MD CM FRCPC David N. Juurlink MD PhD FRCPC Barry Power PharmD
Tara Gomes MHSc Nicholas Pimlott PhD MD CCFP



RESEARCH

Trends in opioid use and dosing among socio-economically disadvantaged patients

TARA GOMES, DAVID N. JUURLINK, IRFAN A. DHALLA, ANGELA MAILIS-GAGNO
J. MICHAEL PATERSON, MUHAMMAD M. MAMDANI

Addiction
RESEARCH REPORT
doi:10.1111/add.1259

The burden of premature opioid-related mortality

Tara Gomes[1,2,3,4], Muhammad M. Mamdani[1,2,3,5,6], Irfan A. Dhalla[1,2,5,7], Stephen Cornish[8], J. Michael Paterson[1,9] & David N. Juurlink[1,2,4,7]

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Cardiovascular Health

Research

A Section 508–conformant HTML version of this article is available at http://dx.doi.org/10.1289/ehp.1510425.

Moving to a Highly Walkable Neighborhood and Incidence of Hypertension: A Propensity-Score Matched Cohort Study

Maria Chiu,[1] Mohammad-Reza Rezai,[1] Laura C. Maclagan,[1] Peter C. Austin,[1] Baiju R. Shah,[1,2,3] Donald A. Redelmeier,[1,4] and Jack V. Tu[1,2,5]

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Incidence of Major Cardiovascular Events in Immigrants to Ontario, Canada

The CANHEART Immigrant Study

Jack V. Tu, MD, PhD; Anna Chu, MHSc; Mohammad R. Rezai, MD, PhD; Helen Guo, MSc; Laura C. Maclagan, MSc; Peter C. Austin, PhD; Gillian L. Booth, MD, MSc; Douglas G. Manuel, MD, MSc; Maria Chiu, PhD; Dennis T. Ko, MD, MSc; Douglas S. Lee, MD, PhD; Baiju R. Shah, MD, PhD; Linda R. Donovan, BScN, MBA; Qazi Zain Sohail, BSc; David A. Alter, MD, PhD

BMJ Open

Temporal trends in cardiovascular disease risk factors among white, South Asian, Chinese and black groups in Ontario, Canada, 2001 to 2012: a population-based study

Maria Chiu,[1] Laura C Maclagan,[1] Jack V Tu,[2,3,4] Baiju R Shah[1,5]

ICES Data & Analytic Services (DAS)

- **Established in 2014**
- **Part of Ontario's Strategy for Patient Oriented Research (SPOR)**
- **Separate unit within ICES**
- **Supports access to researchers external to ICES**

Available Services

- **Access to data**
  - Highly de-identified and risk reduced data uploaded to secure virtual environment
  - Researcher performs analyses using analytical software and produces reports within the environment
  - Only available to Canadian researchers

- **Analytics and reports**
  - Analyses performed by ICES DAS Analysts
  - Deliverables generated according to analytic plan designed by Researcher

Available Services

- **Data linkage**
  - Importation and linkage of external data
  - Specific project use
  - Requires Data Sharing Agreement

Stakeholder Perceptions

- **Ongoing collection by both public and private sectors**
- **Data linkage necessary for planning and system monitoring**
- **Concerns about identifying information**
- **Research**
    - Industry: profit-driven
    - Government/academic: more impartial

DAS Private Sector Pilot

- **Guided by three principles:**
  - Alignment with ICES mission, vision, values
  - Transparency
  - Supplementary to core ICES work
- **Analysis & Reporting services only**
- **Opened May 2016**

DAS Private Sector Projects

- **REB approval required**
- **Study design and methodology provided by private sector client**
- **No collaboration with ICES scientists**
- **No publication requirements**
- **Timelines depend on study**
- **Costs higher than public sector studies**
- **Subset of repository available**

Conclusions

- **Landscape is changing – ICES is one of many**
- **Expanding access, but still in pilot phase**

Acknowledgements

Thank You

Contact us at das@ices.on.ca

The Future of Health Data Accessibility in Canada

Canadian Association of Population Therapeutics

CIHI: Data access for data use

Stephen O'Reilly, Executive Director/Associate CIO

Canadian Institute for Health Information

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CIHI

Outline

CIHI strategic plan

Making it easier to access and use data

Myth Busting: timeliness, ease, breadth

Demonstration: dashboards, tools and uptake

CIHI's Strategic Plan 2016 to 2021

Vision

Better data.
Better decisions.
Healthier Canadians.

Mandate

Deliver comparable and actionable information to accelerate improvements in health care, health system performance and population health across the continuum of care

Strategic goals

- Be a trusted source of standards and quality data
- Expand analytical tools to support measurement of health systems
- Produce actionable analysis and accelerate its adoption

Priority themes and populations

Themes

Patient experience
Quality and safety
Outcomes
Value for money

Health system performance

Populations

Seniors and aging
Mental health and addictions
First Nations, Inuit and Métis
Children and youth

Foundation

Our people
Stakeholder engagement and partnerships
Privacy and security
Information technology

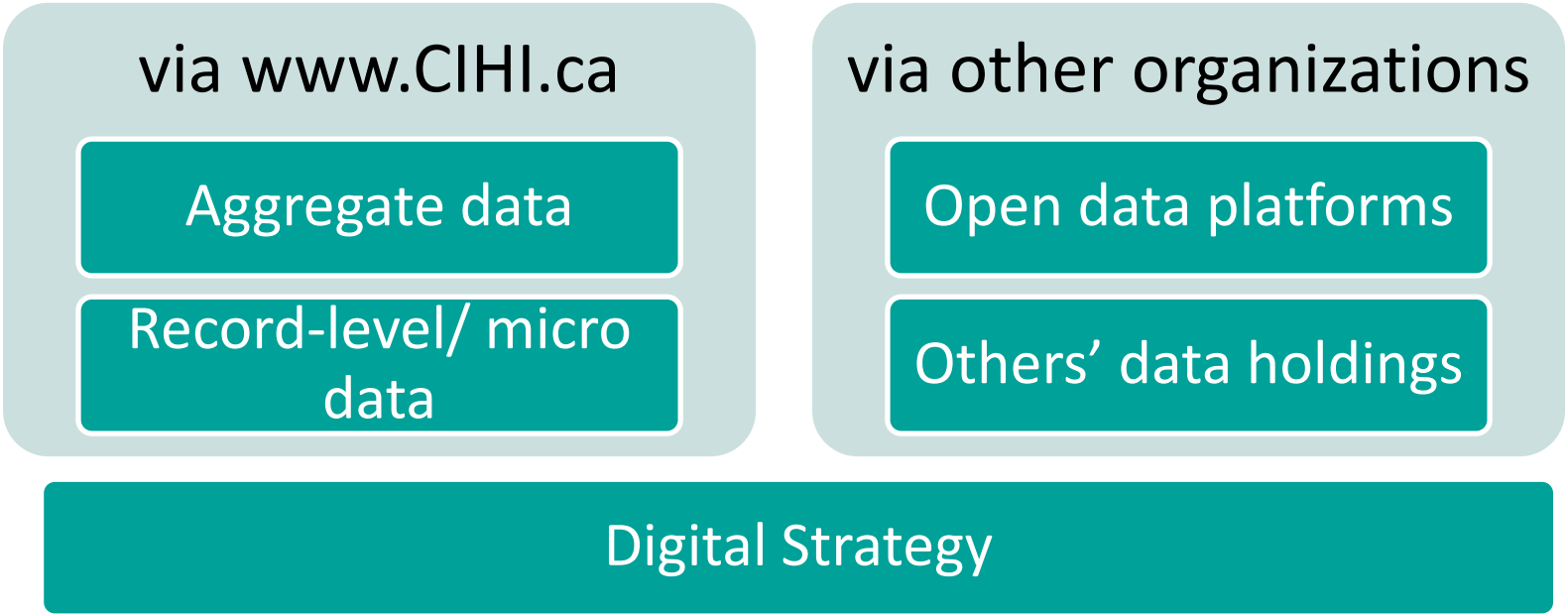
Values

Respect • Integrity • Collaboration • Excellence • Innovation

CIHI

Vision forward: Make data more accessible

Goal: Easy, timely and appropriately tailored access to CIHI data, with an increasing reliance on self-service, where appropriate



CIHI's contributions

CIHI is a prescribed entity and therefore a custodian of health information.

- A Pan-Canadian perspective allows us to bring together comparable data from multiple sectors
- Access to data program – Vision: linkages across the continuum (home care, long term care, acute care)
- Value–added tools, methodologies and products to support analysis of the data
- Standardized data collection

Working with our partners

We work with long-standing partners including Industry, Statistics Canada, ICES, CIHR, and provincial research centres

- Renewed support for the research community through our Data Liberation Initiative
- Newest initiative includes work with Statistics Canada to pilot linked CIHI data in secure Research Data Centres
- Graduate Student Data Access Program
- Support for research initiatives such as the Strategy for Patient Oriented Research (SPOR)

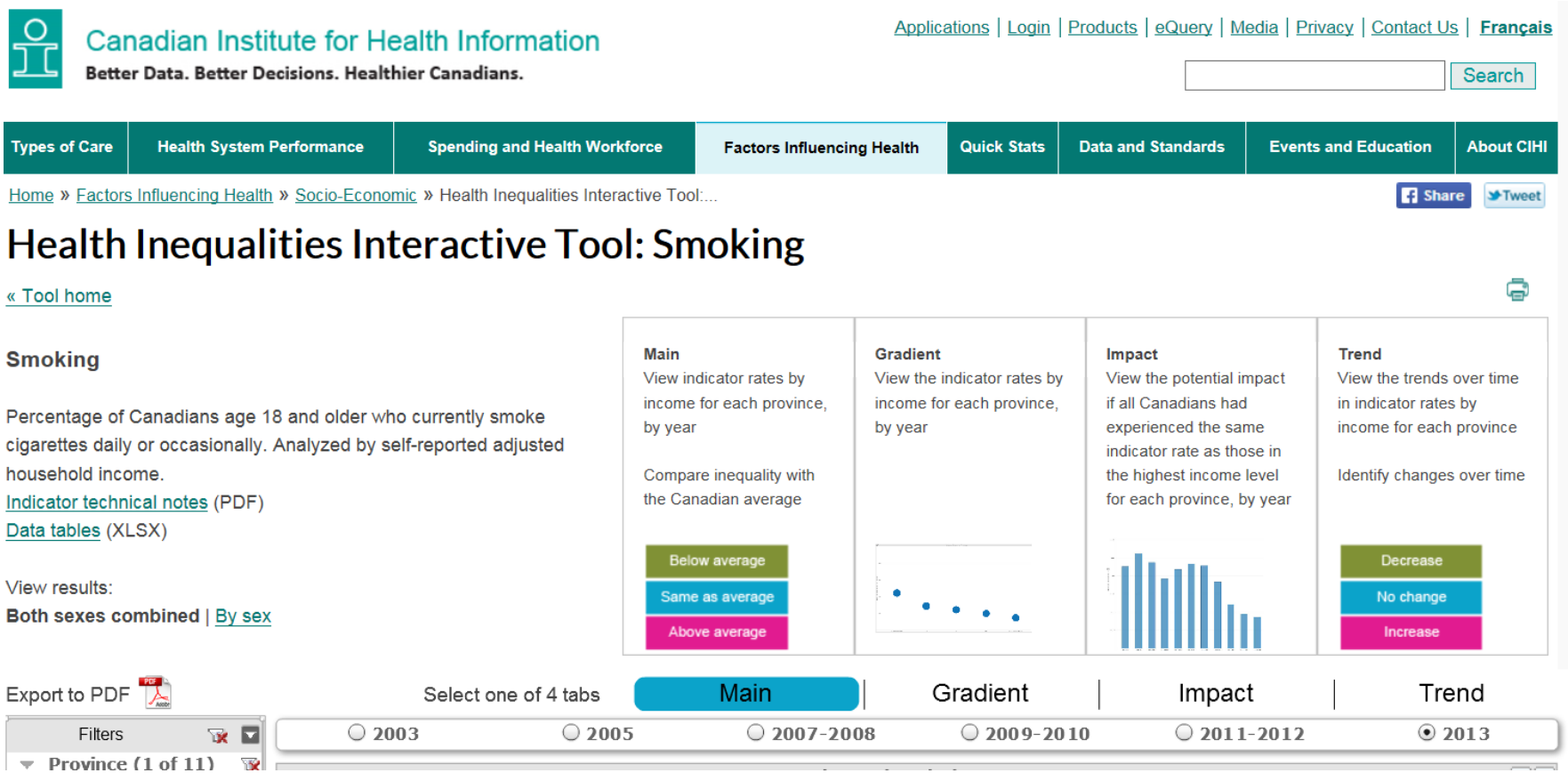
Myth-busting

Timeliness	Ease	Breadth
• Access to “open year” data • Established performance targets to meet customer needs • Service standards for straight-forward, complex and very complex data requests • Better response to all requests	• Public-use dashboards and web tools • Enhanced functionality of the Portal tool	• Access to complex linked data • Linkages with data from other organizations • Data on multiple aspects of health care across the continuum (home care, LTC, acute care, workforce and financial data etc.)

Many ways to access CIHI data

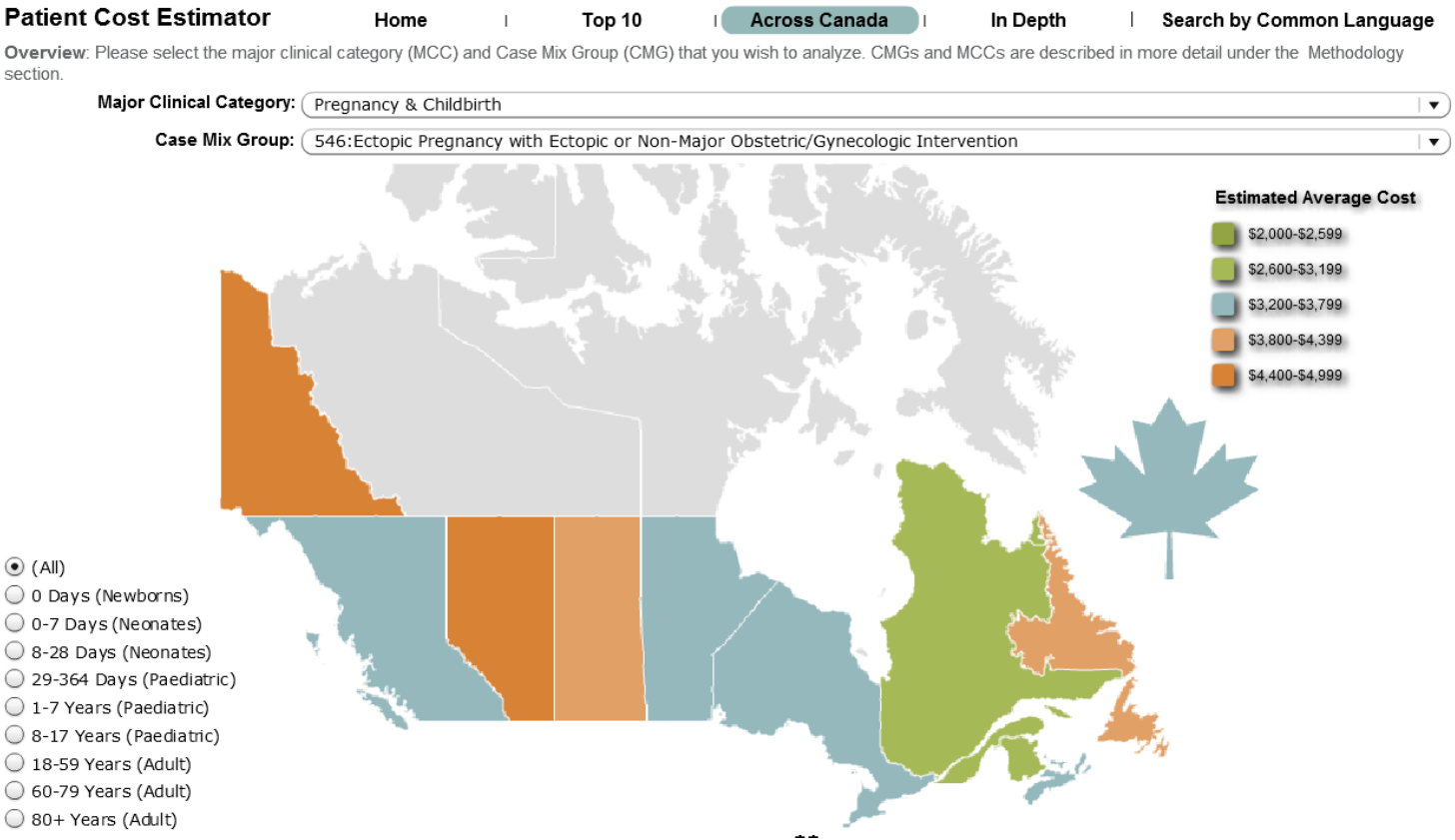
Publicly available: Interactive reports and analytical tools	**Publicly available: Quick Stats and Analytical publications**	**Data accessible to CIHI Clients**
Wait times: Interactive report presents wait times as provinces work to meet benchmarks for priority procedures in Canada	Quick Stats are a series of free, publicly available, aggregate-level reports about Canada's health care statistics.	Collaborative with Statistics Canada's Data Liberation Initiative (DLI):
Patient Cost Estimator: Estimates the average cost of various services provided in hospitals	Quick Stats are available in two formats: An **interactive** format and a **static** format with information in tables that are easy to print.	Visit our data holdings to access secure, interactive, web-based e-reports.
CIHI's Indicator Library for definitions, methodologies and the location of indicator results on CIHI's website and Your Health System site	Published topic-specific analytical reports and products present figures, graphs, tables and accompanying narratives	CIHI Portal provides access to enriched, facility-identifiable data on the delivery of services by Canada's hospitals.

Breadth and wealth of CIHI data



Source: www.cihi.ca

Patient Cost Estimator



OECD Interactive Tool

Comparing the Provinces with OECD Countries

Source: www.cihi.ca

CIHI

Canadian Institute for Health Information

Better data. Better decisions. Healthier Canadians.

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