Big Data and Big Privacy in Brain Disorder Research: Changing the System

OECD 2013

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June 3, 2013
• Gathering big data in health research must be driven by a scientific vision

• The achievement of this vision requires system innovation
The OBI Story - Outline

- Reason for the existence of OBI and principles of development
- The System Change – and how it leads to the need for big data
  - Brain-CODE: the OBI response to the need
- Key issues – and still learning
The OBI is...

- Embedding research into clinical practice and care
- Embedding commercialization into research
OBI’s Innovation System harnesses ideas, people and infrastructure from all sectors in Ontario.

- Galvanize pan-Ontario partnerships; engage with the world.
- Encouraging early and active industry partnership to get promising ideas to markets—and patients—faster.
- Improving entrepreneurial and management capacity to build a thriving knowledge economy and neurocluster in Ontario.
- Putting patients at the centre of a multi-dimensional approach to the investigation of critical brain disorders.
- Standardizing clinical data to accelerate discovery, improve patient care and foster healthcare efficiencies.
- Enable knowledge translation and catalyze education for the public.
- High-impact translational programs
- Centralized patient information systems
- Mechanisms to engage and support industry
- OBI’s Goal: Improve brain health

High impact translational programs
Centralized patient information systems
Mechanisms to engage and support industry
Training and entrepreneurship
Enable knowledge translation and catalyze education for the public.

OBI’s Innovation System harnesses ideas, people and infrastructure from all sectors in Ontario.
OBI’s Innovation System is built on collaboration and partnership

OBI’s Goal:
*Improve brain health*

**High-impact translational programs**

**Centralized patient information systems**

**Mechanisms to engage and support industry**

**Catalyze**

**Empower**

**Integrate**

- Galvanize pan-Ontario partnerships, engage with the world.
- Enable knowledge translation and catalyze education for the public.
- Encouraging early and active industry partnership to get promising ideas to markets—and patients—faster.
- Standardizing clinical data to accelerate discovery, improve patient care and foster healthcare efficiencies.
- Putting patients at the centre of a multi-dimensional approach to the investigation of critical brain disorders.

**Improving entrepreneurial and management capacity to build a thriving knowledge economy and neurocluster in Ontario.**
Collaboration and partnership

- Eliminate silos among institutions, industry/research, scientists/clinicians
- Galvanize pan-Ontario partnerships among:
  - Researchers
  - Clinicians
  - Industry
  - Patient Advocacy Groups
  - Government
  - Philanthropy
  - Non-governmental organizations
OBI’s Innovation System harnesses ideas, people and infrastructure from all sectors in Ontario.

**OBI’s Goal:**

- **Amplify**
  - High-impact translational programs

- **Empower**
  - Improving entrepreneurial and management capacity to build a thriving knowledge economy and neurocluster in Ontario.

- **Integrate**
  - Galvanize pan-Ontario partnerships; engage with the world.

- **Catalyze**
  - Mechanisms to engage and support industry

- **Centralize**
  - OBI’s Goal: Improve brain health
  - Patient information systems

**Putting patients at the centre of a multi-dimensional approach to the investigation of critical brain disorders.**

- Standardizing clinical data to accelerate discovery, improve patient care and foster healthcare efficiencies.

- Encouraging early and active industry partnership to get promising ideas to markets—and patients—faster.
“Recognizing that neuroscience is not, of course, really a single field is important. Rather, it is a multidisciplinary enterprise including diverse fields of biology, psychology, neurology, chemistry, mathematics, physics, engineering, computer science and more.

If scientists within neuroscience and related disciplines could unite around a small set of goals, the opportunity for advancing our understanding of brain and mental function would be huge.”

A different look at brain disorders

- Brain disorders are heterogeneous from genes to pathology to social and individual expression.

- Research system must allow investigation not only within a disease, but across diseases.

- Provides potential for “Precision Medicine” – or at least subgroup stratification – as well as studying the markers (bio, psychological, social....) underlying disease/disorder development and expression.
Neurodegeneration Steering Committee:
Michael Strong (Program Lead), Sandra Black, Dale Corbett, Rob Hegele, Tony Lang, David Park & Barry Greenberg

Collaborating Clinical & Patient Sites
- Baycrest
- Bruyère Continuing Care
- CAMH
- Centre For Movement Disorders
- Hamilton Health Sciences Centre
- London Health Sciences Centre
- Mt. Sinai Hospital
- Ottawa General Hospital
- Parkwood Hospital
- St. Joseph’s Health Centre
- St. Michael’s Hospital
- Sunnybrook
- Toronto Western Hospital

Key Facts:
- 42 Core Clinicians and Researchers
- 13 Clinical Sites
- 9 Patient Advocacy Groups
- $150,000 initial investment by OBI (next funding priority)

Collaborating Academic Institutions
- McMaster University
- Ottawa Research Institute
- Queen’s University
- Robarts Research Institute
- Rotman Research Institute
- University of Ottawa
- University of Toronto
- University of Waterloo
- Western University
Disease-themed, multidisciplinary collaborations collecting multiple modalities of data
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Brain-CODE enables researchers to explore new and complex relationships, leading to new avenues of research and treatment.
Data must be generated for specific reasons and objectives

Data must be useable (quality of data) – and used!

Analysis of data must considered in the development

Results of initial analyses must be validated and replicated
Brain-CODE: The Definition

Brain-CODE is an extensible open access informatics platform that manages acquisition and storage of multidimensional data collected from patients with a variety of brain disorders.
**Brain-CODE: Core principles**

- **Expert Leadership**: International Advisory Committee, *InDOC* Consortium of Ontario not-for-profits, who are building Brain-CODE

- **Privacy and Security**: Adheres to the highest standards of privacy and security – Designated “Privacy by Design” Ambassador, extensive policy framework and governance apparatus

- **Federation**: Designed to link with external databases to leverage existing resources, augment data holdings and provide for richer analytics

- **Standardization**: Common Data Elements (CDEs) and other measures implemented throughout the ‘system’ to provide effective comparison across disorders and databases

- **Analytics**: Amplified research outcomes - looking to create the right strategy and partnerships for a powerful analytics infrastructure
OBI’s solution

Brain-CODE: Inputs and outputs

Ontario

External databases

Brain-CODE

External researchers

Other ID Program researchers

External researchers

NDAR

ADNI

OHS

CLSA

Neurodegeneration

POND

Epilepsy

CP-NET

Depression

Concussion

Addiction

ID programs

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**BIG DATA:** Often used as generic term. Refers to sets of data that are so large that they require special tools to process. Our big data comes in *two flavours*:

1. **DEEP DATA:** Research data that provides an in-depth characterization of individuals (e.g., genetics, imaging)

2. **BROAD DATA:** Lifelong healthcare data for over 13 million people (e.g., physician visits, hospital and ER visits, drug prescriptions, long-term and home care, etc.)
BROAD + DEEP = UNPRECEDENTED
• Health services research (e.g., costs and quality of care)
• Evaluation of health systems policies (e.g., cost of care for people with dementia)
• Understanding and treating diseases based on mechanisms vs. behaviours
• Clinical trials (e.g., recruitment of well-defined patients whose complete healthcare history is known)
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Key Issues – and still learning

- Yakabuski – Globe and Mail:
  - “Big data should inspire humility, not hype”
  - risk – confusing correlation with causation

- Answer: The System should be organized to promote not only data mining for discovery, but hypothesis testing, replication
The Information and Privacy Commissioner of Ontario:

“The revolution that big data could bring about in medicine, commerce and science can only be realized when *Big Data is coupled with Big Privacy*”

*Answer: Design for security*
Key Issues – and still learning

- Ethics, sharing data, personal health information; 84% of Canadians support use of their personal data for health care research (Angus Reid Public Opinion Poll);

- Answer: must be gatekeepers: we established principles, ensured safeguards, enlisted aid of Information and Privacy Commissioner of Ontario – and still learning!

- Need support of universities/hospitals for data transfer and sharing agreements
- Big insights will be gained not from big data alone, but ...

- From big data gathered from strategic systemic change
Thank You

For additional info, contact
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Core configuration

Data acquisition and management through validated applications; customized data integration and portal systems.
Federation

- Federating Brain-CODE’s data with other databases
  - Leverages existing resources
  - Augments our data
  - Richer data for analytics
- We will be federating with multiple strategic partners and plan to expand