Beyond Open Data
How Open Science Aims to Transform Science Partnerships

E. Richard Gold
James McGill Professor, Faculty of Law & Dep't of Human Genetics, Faculty of Medicine, McGill University

National Data Services Framework Summit 2019
January 24-25, 2019

McGill

cipp

CENTRE FOR INTELLECTUAL PROPERTY POLICY

Data is not enough

McGill

cipp

CENTRE FOR INTELLECTUAL PROPERTY POLICY

McGill cipp

CENTRE FOR INTELLECTUAL PROPERTY POLICY

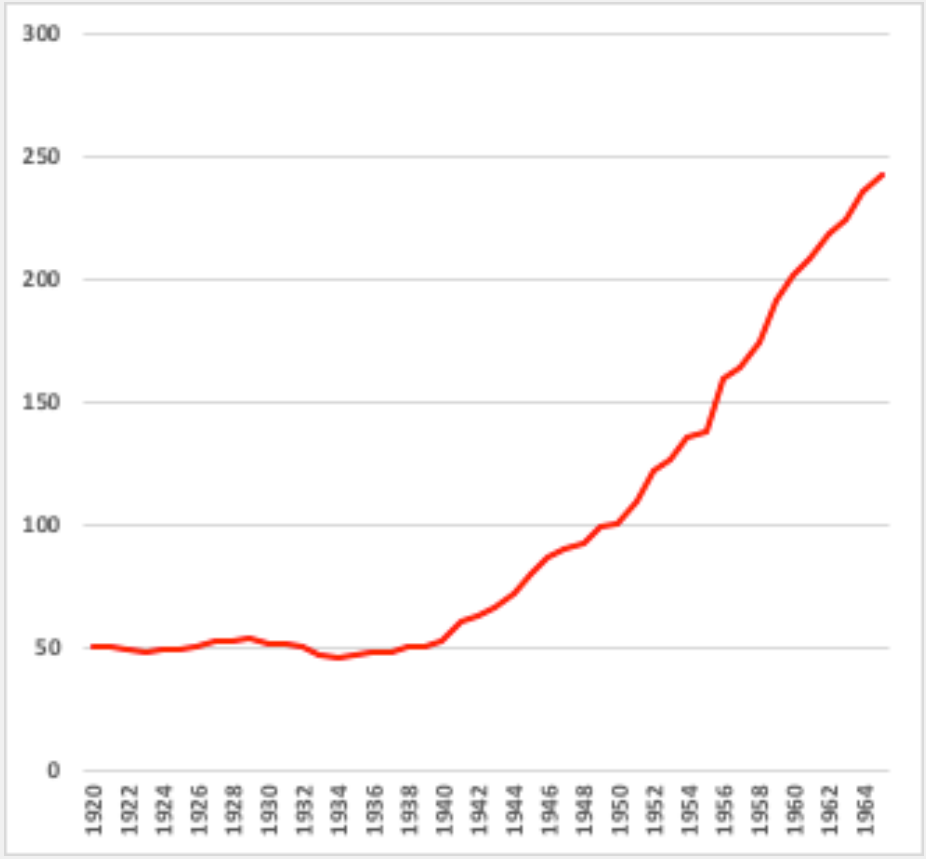
Drivers

- Exponentially increasing costs of research
- Flat or decreasing research productivity

➢ We spend more to get less

➢ Innovation contributing much less to economic growth than 50 years ago

R&D Expenditure per Technical Person: 1920-1965

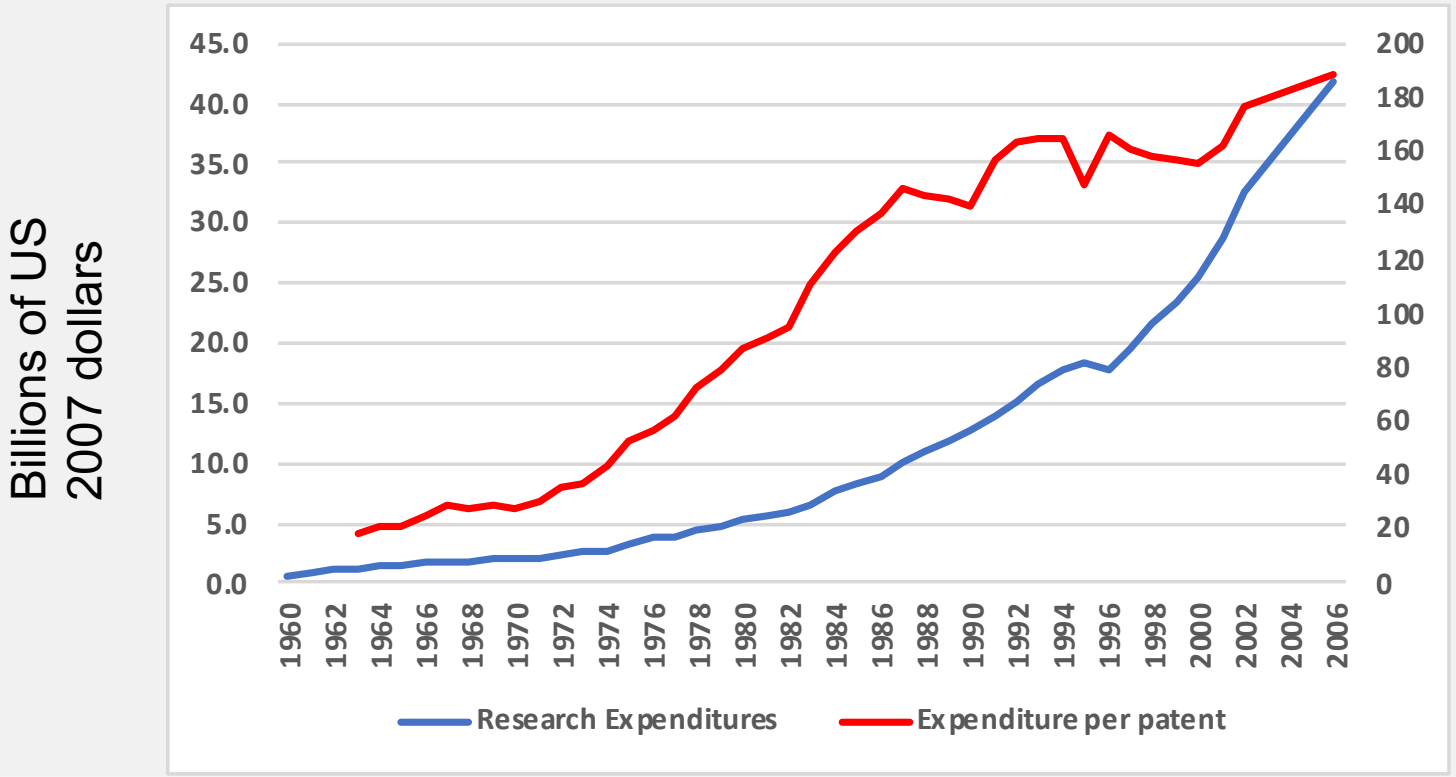


Milton, Helen S. 1966. Cost-of-Research Index 1920-1965. Research Analysis Corporation

McGill cipp

CENTRE FOR INTELLECTUAL PROPERTY POLICY

US Medical Research Expenditures, Medical Research Expenditures/all domestic patent applications: 1960-2006

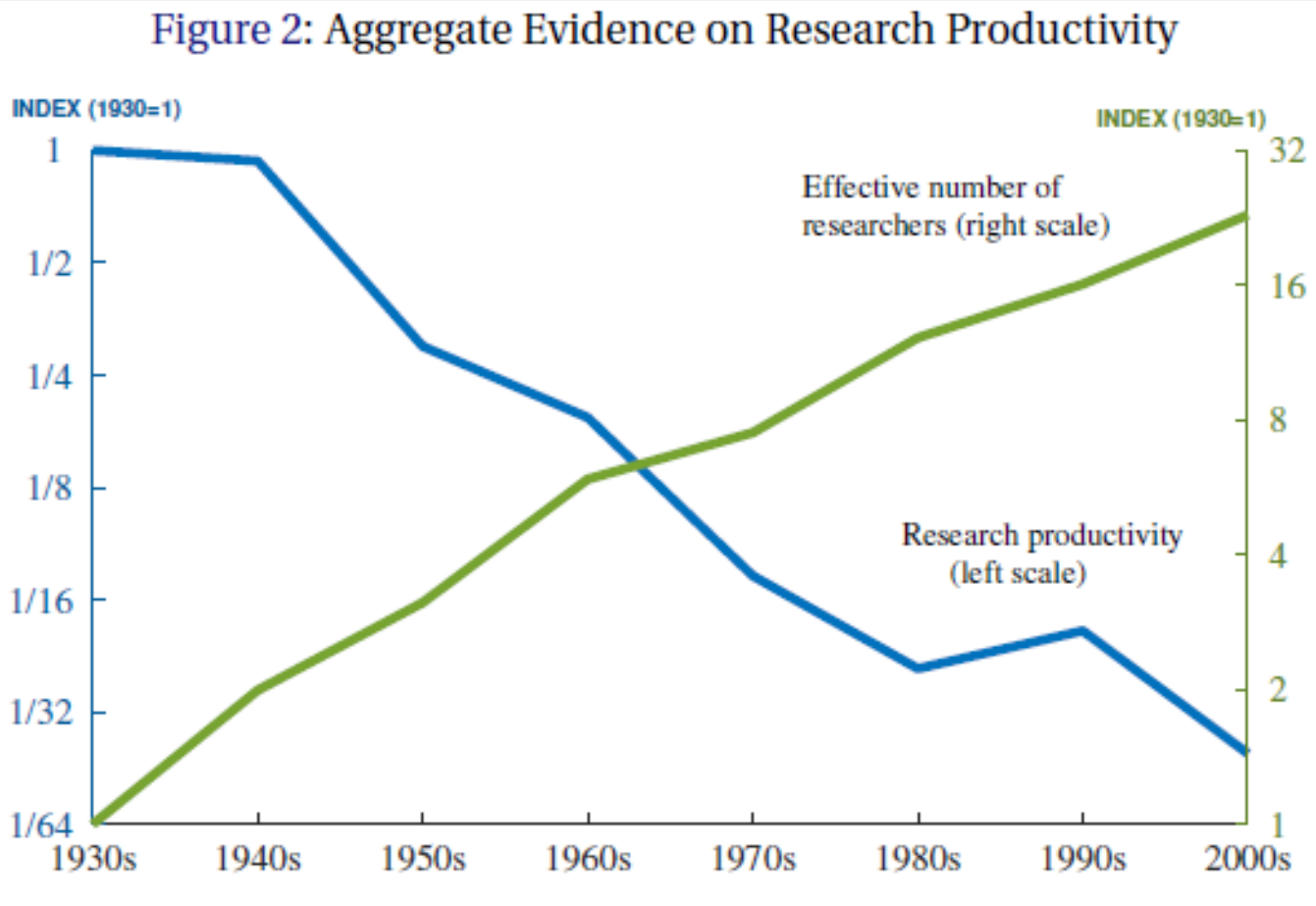


Data from Statistical Abstract of the United States: 2010 (129th Edition), table 127, National Health Expenditures--Summary, and Projections; USPTO U.S. Patent Statistics Chart 1963-2015

McGill

cipp

CENTRE FOR INTELLECTUAL PROPERTY POLICY

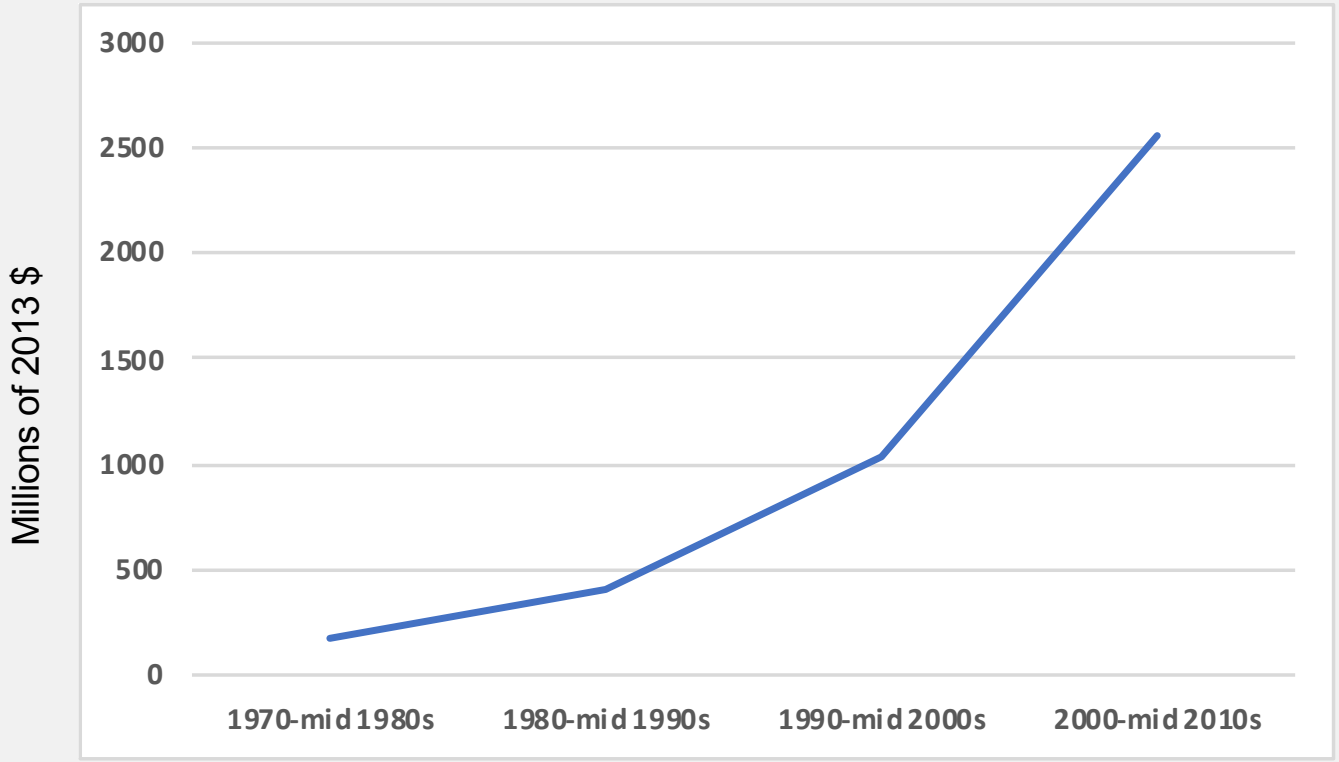


Nicholas Bloom, Charles I Jones, John Van Reenen & Michael Webb, "Are Ideas Harder to Find?" (2017) Version 2.0 at 9.

McGill cipp

CENTRE FOR INTELLECTUAL PROPERTY POLICY

Cost per Approved New Drug: 1970-mid 2010s

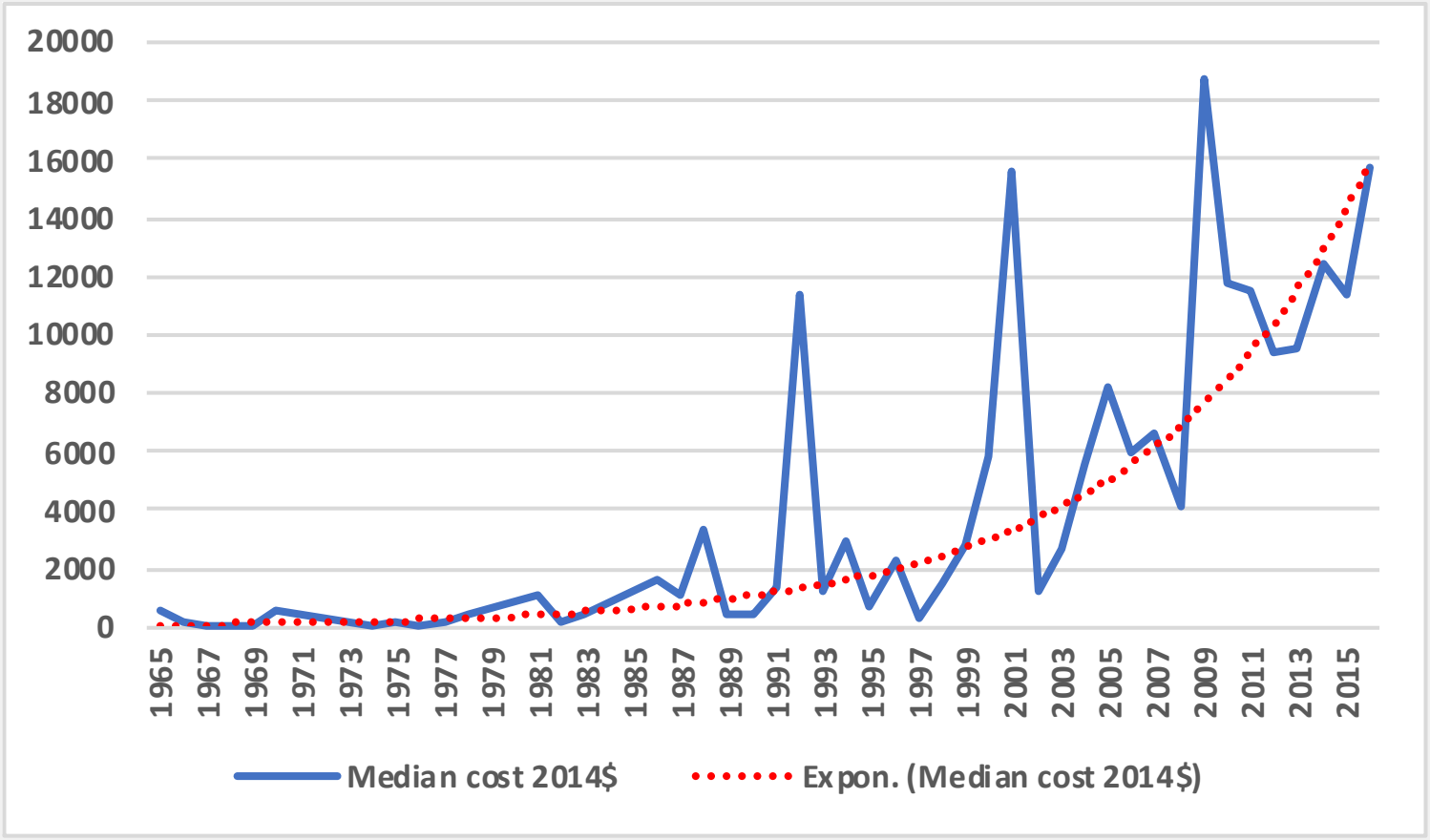


DiMasi, JA, Grabowski, HG, and Hansen, RW. 2016. Innovation in the pharmaceutical industry: New estimates of R&D costs. Journal of Health Economics 47:20-33

McGill cipp

CENTRE FOR INTELLECTUAL PROPERTY POLICY

Median monthly cost of cancer drugs: 1965-2016



Data from Peter B. Bach, MD, Memorial Sloan Kettering Cancer Center

McGill

cipp

CENTRE FOR INTELLECTUAL PROPERTY POLICY

Contribution of Innovation to the Economy

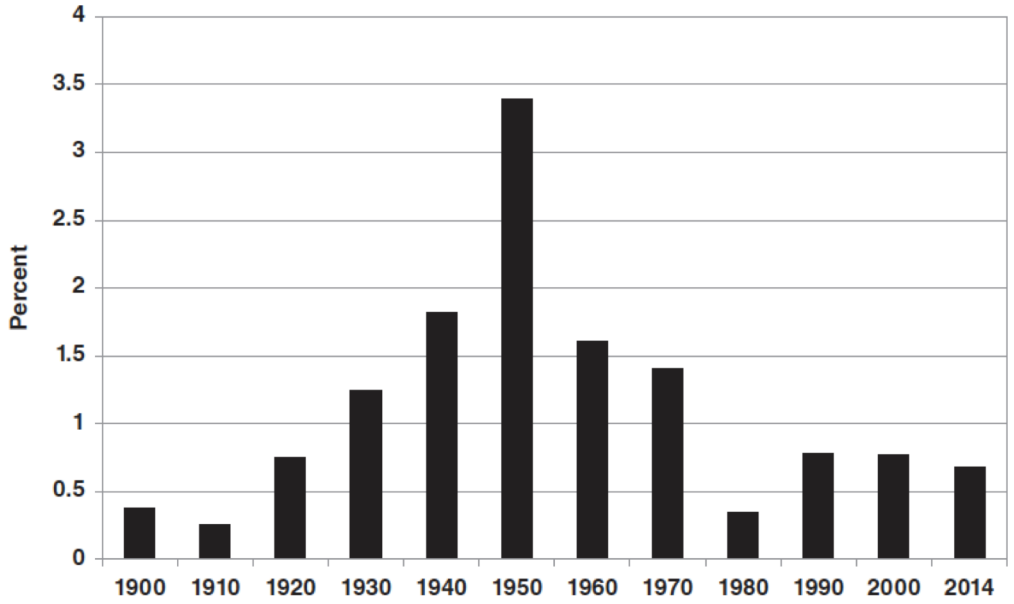


Figure 16–5. 10-Year Average Annual Growth in Total Factor Productivity, 1900–2014

Note: The average annual growth rate is over the ten years prior to year shown. The bar labelled 2014 shows the average annual growth rate for 2001–14.

Robert Gordon, The Rise and Fall of American Growth: The U.S. Standard of Living since the Civil War, 2016

McGill cipp

CENTRE FOR INTELLECTUAL PROPERTY POLICY

Edwards et al. 2011. Too many roads not taken. *Nature* 470, 163–165

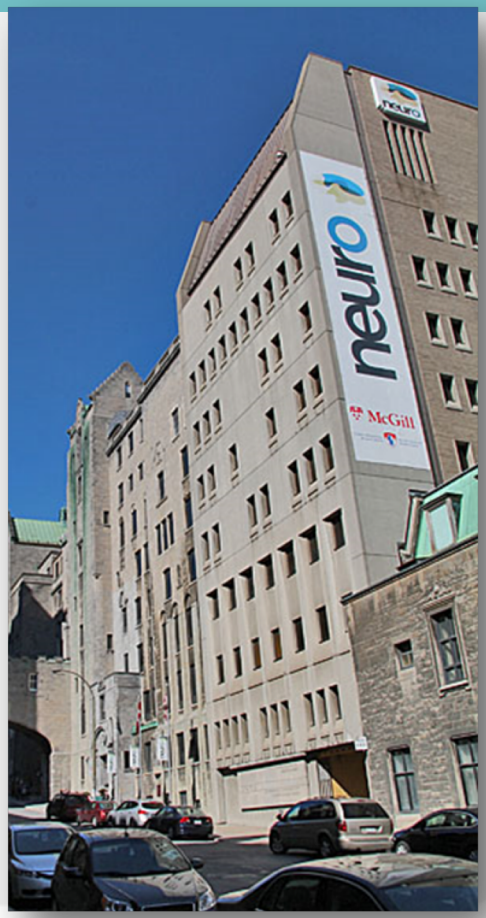
McGill cipp

CENTRE FOR INTELLECTUAL PROPERTY POLICY

The Montreal Neurological Institute & Hospital

"The Neuro":

- Founded in 1934 by neurosurgeon Dr. Wilder Penfield
- World-renowned neurological institute integrating neuroscience research in a clinical setting
- Unique breadth of expertise from genes to cells to animal models to patients
  - **A nearly 100 year-old history of providing excellence in clinical care while simultaneously empowering patients by allowing them to participate in research**



McGill cipp
CENTRE FOR INTELLECTUAL PROPERTY POLICY

A Combined Research Institute and Specialized Hospital

Academic Mission:

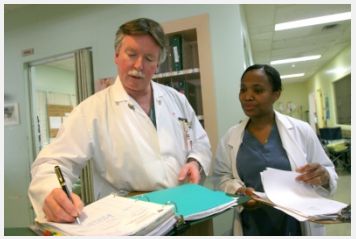
- 105 Faculty including 15 clinician scientists
- 60 faculty-led labs
- 189 graduate students and postdoc fellows

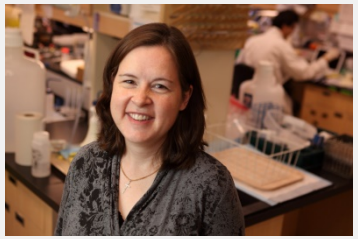
Total research staff ~ 580

Clinical Mission:

- 61 physicians including 15 clinician scientists
- 13 Neurosurgeons and 31 Neurologists
- 41 residents & fellows
- 450 nurses & 41 Allied health & support staff (FTE)

Total clinical staff ~ 600





CENTRE FOR INTELLECTUAL PROPERTY POLICY

A Desperate Need

- Despite being a growing burden to society, most neurological diseases lack effective treatments / therapies
- Estimated cost of neurological diseases = $23B annually
- Diseases of the brain predicted to surpass cancer as the second leading cause of death in Canada by 2040

Patients, families, and clinicians share a sense of **frustration and urgency**

McGill cipp
CENTRE FOR INTELLECTUAL PROPERTY POLICY


"The best thing to do with your data
will be thought of by someone else."
~Rufus Pollock @rufuspollock

Focus on openness

- Open innovation: licensing in/out to maximize value of patent portfolios
- Open access: making copyrighted works available free to user at cost to author
- Open data: making data freely available through databases at someone's cost

Sharing Data is not enough

Netflix

McGill

cipp

CENTRE FOR INTELLECTUAL PROPERTY POLICY

Open Access

- Does not change type of audience
- Does not change focus, language, assumptions

➢ May speed up dissemination

Beyond Data

- Diversify partners and knowledge
- Reduce transaction costs
- Engage broader audiences
- Reconceptualize problem and answers

➢ Open Science Partnerships

Open Science Definitions

- Multiple definitions of open science:
  - A way of doing science (e-notebooks, data sharing, citizen science, etc.)
  - A way of structuring relationships between partners to achieve common end

Our Definition

Open Science (OS) comprises a set of institutional policies, infrastructure and relationships related to open access publication, open data and scientific resources, and lack of restrictive intellectual and other proprietary rights with the goal of increasing the quality and credibility of scientific outputs, increasing efficiency, and spurring both discovery and innovation

McGill cipp
CENTRE FOR INTELLECTUAL PROPERTY POLICY

Open Science

- **Open access**, **open data** and the **absence of restrictive IP** over core outputs
  - Enabled by policies, infrastructure and relationships
  - Simplified, standard-form agreements
- Open science is goal driven:
  - Increasing **quality** and **credibility** of outputs
  - Diversify ideas, research and outputs
  - Speed up research and innovation
  - Spur **discovery**, **innovation** and **social benefit**

McGill cipp
CENTRE FOR INTELLECTUAL PROPERTY POLICY

MNI Adoption of Open Science

- Top-down and bottom-up processes
- Recognition that open science cannot be imposed but must be adopted
- 18 month process of town halls, independent study, annual meetings
- Started with principles, working on implementation from ground up
- After 2 years, revised and tightened principles

Principle 1: Public release of scientific data and resources

1. Earliest dissemination without compromising quality, confidentiality and attribution
2. Publish in accordance with FAIR principles
3. Centralized support and infrastructure
4. Internal metrics to reward openness within and outside the MNI
5. Funding open access publication
6. Requirement of proper attribution

Principle 2: External research partnerships

- Data, publications and resources released on same basis as Principle 1
- Negative data to be released
- Raw data released when possible
- Clinical trial goals released early

Principle 3: Research Materials and Tools

- Non-exclusive and non-discriminatory access for research purposes
- Some controls on access and charges to cover costs and limited supply
- Encourage further sharing subject to patient consent and confidentiality
- Reward sharing

McGill cipp
CENTRE FOR INTELLECTUAL PROPERTY POLICY

Principle 4: Intellectual Property

- No restrictive intellectual property (IP)
- Partners must agree to this in respect of joint research outcomes
- Will not fund acquisition of restrictive IP
- May take positive steps to ensure freedom to operate

McGill cipp
CENTRE FOR INTELLECTUAL PROPERTY POLICY

Principle 5: Autonomy

- Freedom to opt-out for researchers and patients without prejudice
- Safeguarding the confidentiality and decisional autonomy of participants
- Researchers free to pursue ‘closed’ science outside the institution
- Protecting the career autonomy of trainees

To proof of principle

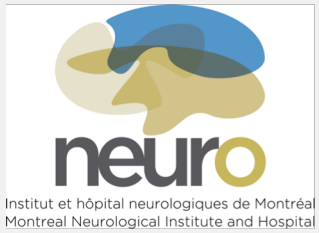
- The MNI & its partner the Structural Genomics Consortium (SGC) are running their OS platforms as a social science experiment
- We have developed a toolkit (quantitative and qualitative) to proactively collect data for analysis on success: https://gatesopenresearch.org/documents/2-66
- Working with funders (gov’ts and philanthropy) to launch OS calls

McGill cipp
CENTRE FOR INTELLECTUAL PROPERTY POLICY

Canada in the lead… for now

- The MNI and SGC are leading the world in implementing open science partnerships from research all the way to innovation
- Other countries are not standing by: OECD, EU Open Science Cloud, NIH Open Science Prize, Wellcome Trust grants, EPFL competition
- At a policy level, Canada falling behind and will be overtaken unless we act decisively
- Will our governments & granting councils act?

McGill cipp
CENTRE FOR INTELLECTUAL PROPERTY POLICY



CENTRE FOR INTELLECTUAL
PROPERTY POLICY