PNWDC CONFERENCE: ETHICS AND PRIVACY FOR SENSITIVE RESEARCH DATA

KAITLYN GUTTERIDGE, RESEARCH DATA PRIVACY AND SECURITY OFFICER, OFFICE OF THE VICE PRESIDENT RESEARCH, UBC

845

29,765,131

TOP FOUR INDUSTRIES (US)

OVERVIEW

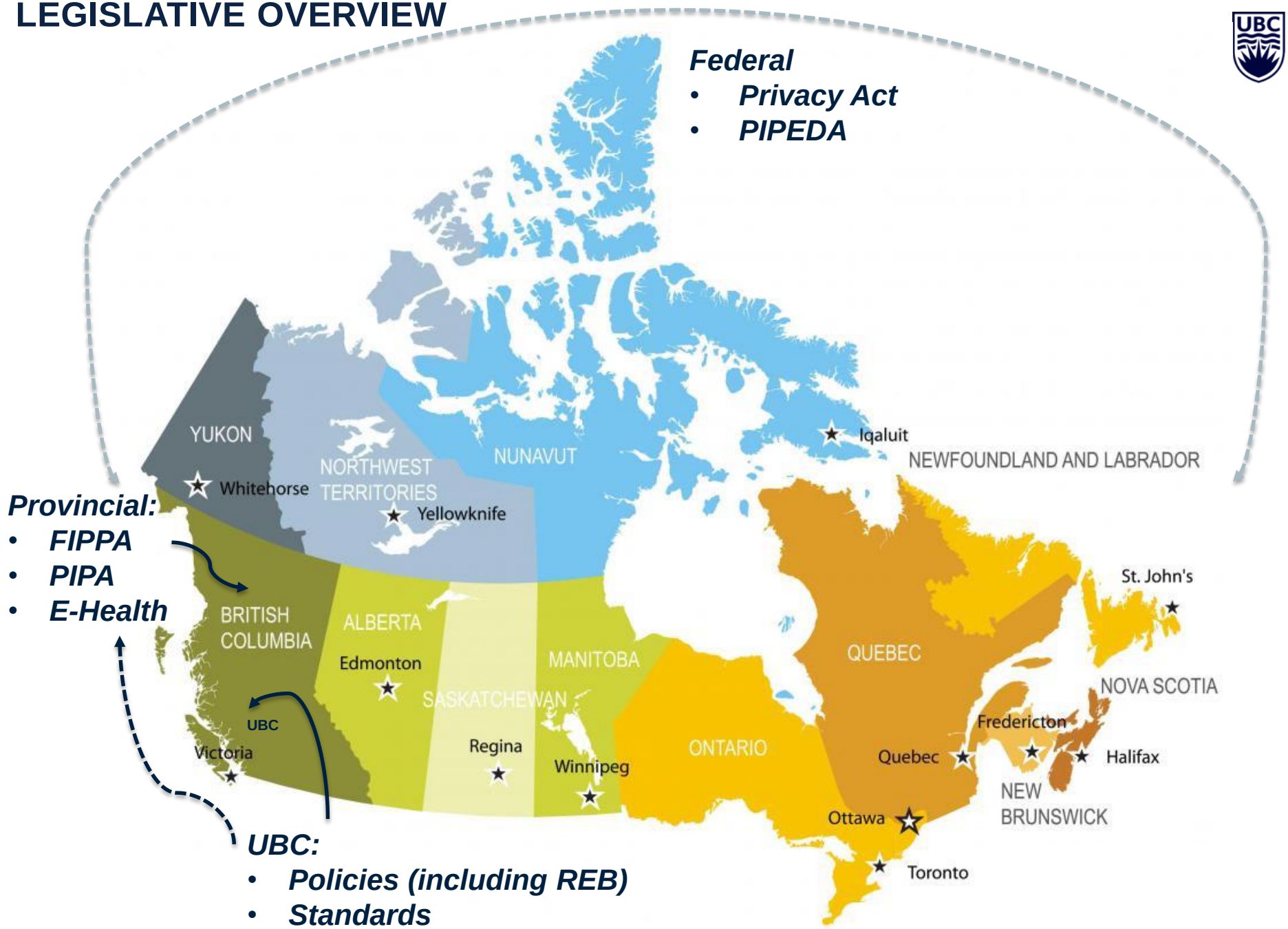
- Getting us all on the same page about privacy, ethics and security
- What the landscape looks like in BC
- How research currently interacts with these components and dilemmas associated with it
- Where are we going?

INFORMATION PRIVACY VS SECURITY VS ETHICS

LEGISLATIVE OVERVIEW

Federal

- ***Privacy Act***
- ***PIPEDA***



Provincial:

- ***FIPPA***
- ***PIPA***
- ***E-Health***

UBC:

- ***Policies (including REB)***
- ***Standards***

BC CONTEXT

- FIPPA purpose:
  - Openness and accountability via right of access to records
  - Protect personal information from unauthorized collection, use, or disclosure

- Personal Information:
  - “Recorded information about an identifiable individual, not including contact information”
    - Business contact vs student information
    - No distinction between PI, PII, PHI
    - Research records

PERSONAL INFORMATION

- The OIPC's identifiability test:
  - *Information will be about an identifiable individual where there is a serious possibility that an individual could be identified through the use of that information, alone or in combination with other available information*

PERSONAL INFORMATION

Which of these would be considered Personal Information?

a. “John Smith is 40 years old.”
b. “Sally Wang is a student.”
c. “Student Number 123456 failed the Biology exam.”
d. “The Dean of the Faculty of Engineering is sick today.”

So…if we have legislation, policies and standards, identifiability tests and best practices to work with, why does research data privacy have to be so complicated?

THE DILEMMA

Legislation doesn't apply to researcher collected data

Required for any research involving humans – limited expertise in privacy

Don't specifically have one for the institution; often de-centralized institutional support

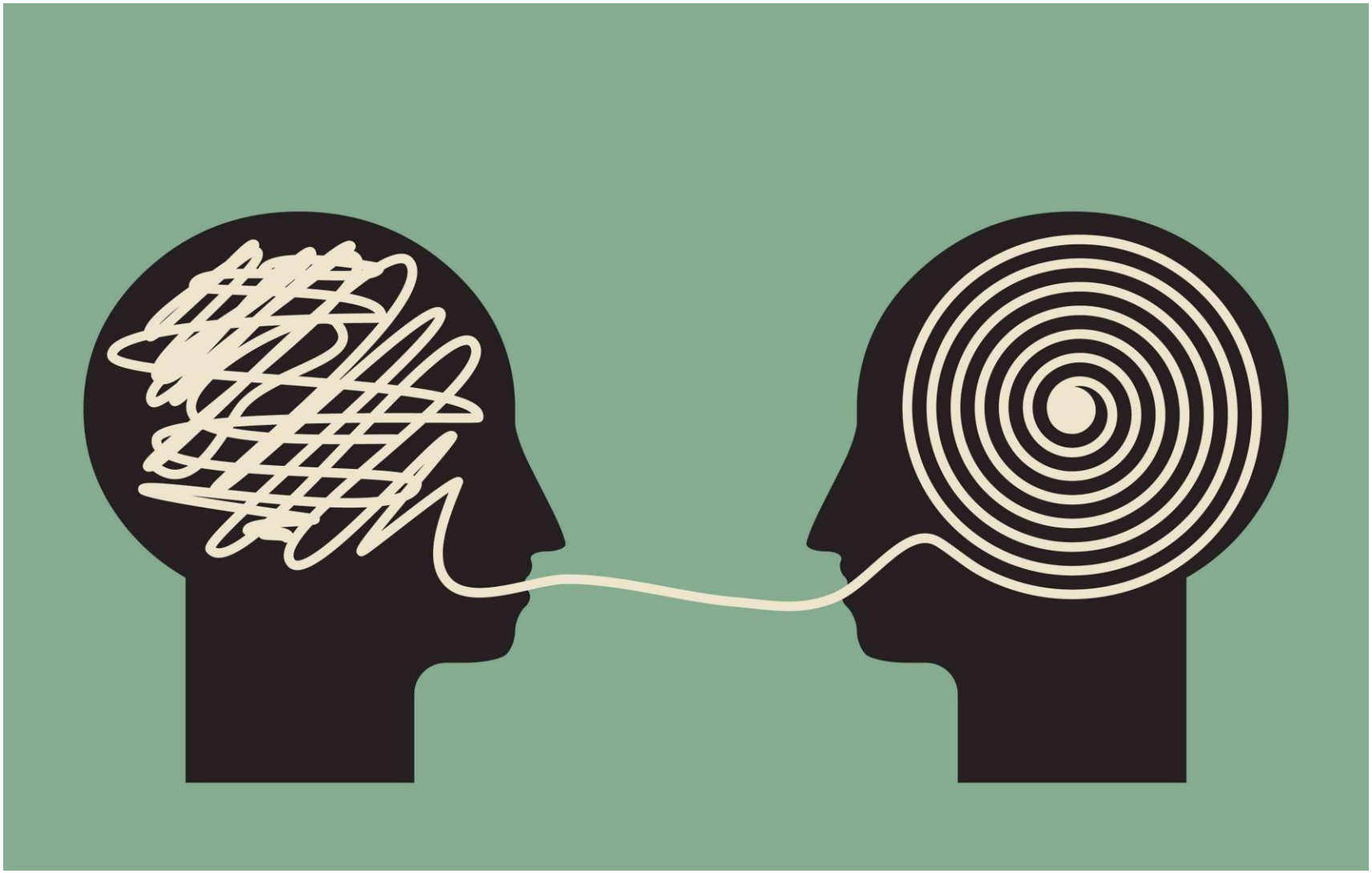
Researchers often don't have funding for proper implementation

Not mandatory to date – should be 2018 for Tri-Agency grants

Linkage, reuse, administrative data sources

Policy for secure storage for minimum five years; open access and data requirements

SO WHAT ARE WE DOING ABOUT IT?



Source: http://www.rachelbernsenat.com/improving-capacity-rational-thinking-letter-nytimes-editor/

Out with the old, in the with new…

DE-IDENTIFICATION IS…"SOMEWHAT USEFUL AS AN ADDED SAFEGUARD" BUT NOT "A USEFUL BASIS FOR POLICY“

- United States President's Council Of Advisors On Science And Technology

More troubling is the broader impact of the heavy reliance on notice and choice. The narrower the scope of notice and consent, the greater the restrictions imposed on future, often unknown uses of data. This can interfere with future benefits and hinder valuable new discoveries. On the other hand, because privacy notices under the 1980 guidelines constrain future data uses, notices have become increasingly broad and permissive. The result has been the increasing erosion of information privacy. In both cases, the reliance on notice and choice has had the effect of shifting much of the responsibility for data protection away from data collectors and data users and onto data subjects.

- Data Protection Principles for the 21st Century (Cate; Cullen; Mayer-Schonberger, 2013)

LAYERED APPROACH

Source: http://www.imshealth.com/sites/en/auxiliary/404

Integration and harmonization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Public Communications
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Conflict of Interest and
Tri-Agency Statement of Principles on Digital Data Management
1. Preamble
The Canadian Institutes of Health Research (CIHR), the Natural Sciences and Engineering Research Council of Canada (NSERC), and the Social Sciences and Humanities Research Council of Canada (SSHRC) (the agencies) are federal granting agencies that promote and support research, research training, knowledge transfer and innovation within Canada.
As publicly funded organizations, the agencies are strong advocates for making the results of the research they fund as accessible as possible. In promoting access to research results, they aspire to advance knowledge, avoid research duplication and encourage reuse, maximize research benefits to Canadians and showcase the accomplishments of Canadian researchers. These aspirations align with the Government of Canada's commitment to open science, as described in Seizing Canada's Moment: Moving Forward in Science, Technology and Innovation(2014).
Research data include observations about the world that are used as primary sources to support scientific and technical inquiry, scholarship and research-creation, and as evidence in the research process.[1] Research data are gathered through a variety of methods, including experimentation, analysis, sampling and repurposing of existing data. They are increasingly produced or translated into digital formats. When properly managed and responsibly shared, these digital resources enable researchers to ask new questions, pursue novel research programs, test alternative hypotheses, deploy innovative methodologies and collaborate across geographic and disciplinary boundaries. The ability to store, access, reuse and build upon digital research data has become critical to the advancement of science and scholarship, supports innovative solutions to economic and social challenges, and holds tremendous potential for Canada's productivity, competitiveness and quality of life.

Adaptability and Transparency

“The technical tools for handling data have already changed dramatically, but our methods and mindsets have been slower to adapt.”

— Viktor Mayer-Schönberger, Big Data: A Revolution That Will Transform How We Live, Work, and Think

Descending Clouds by Gary Hayes (CC BY-NC-ND 2.0) https://flic.kr/p/7RQ4wS

News

Government's Cloud Computing Strategy Focused on Keeping Data in Canada

Trust Is a Must in Business and Life

Source: http://hyken.com/customer-experience-2/trust-is-essential-in-business-and-life/

THANK YOU AND QUESTIONS?

CONTACT INFORMATION:

KAITLYN.GUTTERIDGE@UBC.CA