



UNIVERSITY OF  
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# Security considerations for sensitive human data

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# Overview



- Breadth and depth of human research and the data collected and analyzed
- Ethical policies and standards for the review of human research in Canada
- How Research Ethics Boards (REBs) evaluate sensitivity of data in the context of risk
- REB recommendations for privacy, confidentiality and data security
- Areas of vulnerability/ gaps in knowledge or technology
- Cautionary real-life tales
- Data security as a shared responsibility

# Human research and data

## **Research Methods**

Interventions - clinical and non-clinical

Interactions – focus groups, interviews

Observations – ethnography

Surveys

Face-to-face or virtual, remote or online

Use of smartphones or wearables

Community-engaged

Critical inquiry

Indigenous research

Reuse of data collected for other purposes

Machine Learning, Artificial Intelligence

## **Data collected or obtained**

Personal health information (PHI)

Personally-identifiable information (PII)

Biospecimens

Confidential information

Third party information

Anonymous

De-identified/anonymized

Video recordings

Audio recordings

Photos

Geocodes

Direct quotes, qualitative

Large data sets/ databases

## Research policies and regulations

- Tri-Council policy statement: Ethical conduct for research involving humans
- Privacy legislation
- Tri-Agency RDM policy
- Research Ethics Board (REB) policies, guidelines, other requirements

# Tri-Council policy statement (2018) (TCPS2)

- Requirements for Canadian institutions on conducting and reviewing human research
  - Fundamental principles: Respect for persons, Concern for welfare, Justice
- Research Ethics Board (REB): body to review all human research conducted at or under the auspices of the institution for ethical acceptability
  - Quorum – 5-6 men and women; 2 members knowledgeable in fields and methods, 1 member knowledgeable in law, 1 member knowledgeable in ethics, 1 member not affiliated with the institution and represents the community

# TCPS2

- Privacy – the right to control information about oneself – expressed through consent
- Confidentiality – obligation to safeguard entrusted information
- Security – physical, administrative and technical safeguards of information
- Identifiability:
  - Directly identifiable
  - Indirectly identifiable
  - Coded – direct identifier removed and replaced by a code
  - Anonymized – irrevocably stripped of identifiers, code discarded
  - Anonymous – never had identifiers
- REBs need to determine that researchers have appropriately planned for and will maintain compliance with privacy, confidentiality and data security requirements

# Privacy regulations

- Ontario names, but similar legislation in all provinces and territories
- Personal health information protection act (PHIPA)
  - PHI may be used for research with consent, or REB-approved waiver (under specific conditions) and an REB-approved research plan
  - Ensure that PHI is protected, used only for these purposes and not disclosed or accessed by unauthorized individuals
- Freedom of information and protection of privacy act (FIPPA)
  - Use of administrative records (e.g. student records, grades, HR records) for research purposes is consent-driven or with REB-approved waiver, and an REB-approved research plan
  - PII is protected, used only for approved purposes and not disclosed or accessed by unauthorized individuals

# Tri-Agency research data management policy (2021)

- Research Data Management strategy:
  - Recognize data as an important output
  - RDM practices consistent with other requirements (TCPS2, privacy)
  - Guiding researchers on how to properly manage data, including development of data management plans (DMPs)
  - Recognize that data created through research with Indigenous communities must be managed according to principles and plans designed by these communities
- DMPs: requirement for all researchers to create at the planning stages of the research, and use during and at the end of the research
- Data deposit: all data from Tri-Agency funded research will need to be deposited
- To be phased in starting 2022/2023



# Tri-Agency statement of principles on digital data management

- Importance of making the results of Tri-Agency funded research accessible to other researchers
- Global awareness of the value of digital research data
- Data management planning required
- Must align with other ethical and legal obligations, including TCPS2
- Adherence to international standards; using software and formats that are secure, enable preservation of and access to the data well beyond duration of the project
- Quality metadata should be included, that are in accordance with international and disciplinary best practices to enable future users to understand and reuse
- Publicly accessible, shared as early as possible
- Proper acknowledgement of the source and respect of terms and conditions

# REB management of sensitive data

As determined by:

- Method/sensitivity of the topic
- Location of the research (geo-political context)
- Vulnerability of participant group/data subject
- Identifiability
- Regulations and policies (Canada, and host country)
- Considerations are multi-faceted and nuanced

# REB determination of risk

Group Vulnerability	Research Risk		
	Low	Medium	High
Low	1	1	2
Medium	1	2	3
High	2	3	3

Risk level 1 – minimal risk, reviewed by delegated process – 1-2 members of the REB

Risk levels 2 and 3 – reviewed at full board; subject to post-approval review visits

Research risk is assessed in three ways: physical; psychological/emotional; and social/legal

Sensitivity of data may be influenced by both research risk and group vulnerability

# REB-recommended data security strategies

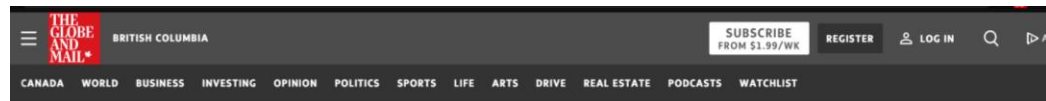
## 1. Limit sensitive data collection

- Only collect as much/what is needed for the research
- Use methods that allow for anonymous data collection (e.g. surveys)
- Use pseudonyms when possible
- Choose a less vulnerable participant group (e.g. advocates)
- Have a management plan, including legal strategy if the data may be of interest to third parties - External pressure to disclose

- Limits further analyses, usefulness of dataset
- Most research requires follow up with participants
- May need specific participant group, otherwise may compromise the research
- Anonymity can lead to poor quality responses
- Pseudonyms may be identifiable, if used often
- Considerations re IP address and other potential identifiers

# External pressure to disclose research data

- Russell Ogden – SFU 1994
- Assisted suicide and euthanasia
- Interviewed individuals involved and witnessed 11 assisted suicides
- Promised “absolute confidentiality” to participants
- Vancouver Coroner subpoenaed Ogden to appear to provide information at an inquest; Ogden refused to reveal identities
- Coroner threatened contempt of court
- Ogden’s legal argument was that his research met the **Wigmore criteria** for confidential privilege
- Buried his research data (physical books) to prevent seizure



## Confidentiality agreement handcuffs prominent assisted-suicide researcher



Russel Ogden, one of the directors of the Farewell Foundation, conducts research involving witnessing assisted suicides.

RAFAL GERSZAK/THE GLOBE AND MAIL

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# External pressure to disclose research data (2)

## Quebec court keeps criminologists' research with Luka Magnotta out of police hands

Adam Feibel © 2014/01/30, 5:39 am



### U of O profs stress importance of confidentiality in criminal investigations

Photo by Adam Feibel

The two University of Ottawa professors who conducted a research study that included an interview with accused killer Luka Magnotta have won their legal bid to quash a Montreal police warrant for the video.

Professors Christine Bruckert and Colette Parent took the matter to court last March in order to

- Christine Bruckert and Colette Parent U of Ottawa 2013
- Went to court to challenge the seizure of a video interview with (now convicted) killer Luka Magnotta
- “Jimmy” was interviewed for “Sex Work and Intimacy: Escorts and Their Clients” that took place between 2004 and 2008
- Magnotta was one of 20 male escorts, 20 female escorts, and 20 clients of escorts who agreed to participate in the study under the promise of confidentiality
- Wigmore criteria used
- Quebec Superior Court Justice ruled that the importance of preserving the relationship between the researcher and the subject outweighed the video’s usefulness to police

## 2. Physical security

- Locked cabinet in locked office for hard copy records
- Clean desk policy
- Secure computers in common spaces
- Do not carry data or unencrypted devices on one's person, or leave in the car



The image is a screenshot of the Toronto Star website. At the top, the "TORONTO STAR" logo is displayed in white on a blue background. To the right of the logo, there is a "Subscribe Now" button with the text "As low as \$1.49/week". Below the logo, a navigation bar contains links for "HOME", "MY LOCAL", "GTA", "CANADA", "POLITICS", "WORLD", "OPINION", "LIFE", "SPORTS", "ENTERTAINMENT", and "BUSINESS". On the right side of the navigation bar, there are icons for "Podcasts" and "Newsletters". The main content area features a "NEWS" tag in a blue box, followed by the headline "Sick Kids doctor loses data on 3,300 patients" in a large, bold, black serif font. Below the headline, there is a small circular profile picture of the author, Megan Ogilvie, followed by the text "By Megan Ogilvie Health Reporter". At the bottom of the article preview, it says "▲ Fri., Aug. 31, 2007 | ⌚ 2 min. read".



### 3. Electronic safeguards

- Encrypt all devices
- Use VPNs when not on a secure server (e.g. for international research)
- Save data onto OneDrive or SharePoint for secure access by team members (DropBox?)
- Acceptable platforms for online research: REDCap (servers at academic institutions), Qualtrics, SurveyMonkey (if using Canadian account)
- Do not use US-based servers for sensitive data, particularly if identifiable or potentially re-identifiable – PATRIOT Act
  - Some regions in Canada won't allow use of online platforms with servers in US, others require disclosure and consent of participants

- Data may not be encrypted when in use, vulnerable to unauthorized access
- Illegal to bring in encrypted devices to some countries
  - Iran, China
- Internet and/or VPNs may be unavailable or unreliable
  - Rural areas
  - Countries with authoritarian regimes – often the focus of the research
- Researchers may be forced to show data at border crossings

## 4. Considerations for virtual research

- Evolution of Zoom for research purposes at Canadian institutions (March 2020 to present)
  - Concerns regarding zoom-bombing, ability to hack transmissions, recordings
  - Now have institutional licenses with password protection
  - Encryption has been improved
  - Questions regarding use for PHI-involved research - sufficient for therapy?
- Setting of where virtual research taking place
  - Privacy for participants and researchers - Can others hear/see conversations?
  - Can researchers see other members of participant's household
  - Problematic for some research

PA Newman, A Guta and T Black. Ethical Considerations for Qualitative Research Methods During the COVID-19 Pandemic and Other Emergency Situations: Navigating the Virtual Field. Int J Qual Methods 2021.

<https://doi.org/10.1177/16094069211047823>

## 5. Analysis of dataset or databases originally collected for other purposes

- Reuse of research data, clinical care (PHI), administration (PII)
- REB considerations for reuse of research data:
  - Broad consent/future use language in consent form
  - Intentions of participants to allow data to be reused, if known
  - REB approval of original project
- REB approval of the research plan for PHI and PII + waiver of consent
  - Can the research be done without a waiver of consent?
  - Potential benefits to society
  - Any foreseeable harms to data subjects
  - Who on research team has authorized access and why
    - must sign contract to maintain confidentiality
  - Data security measures while researcher has data
  - Return or destruction of data at a set time frame

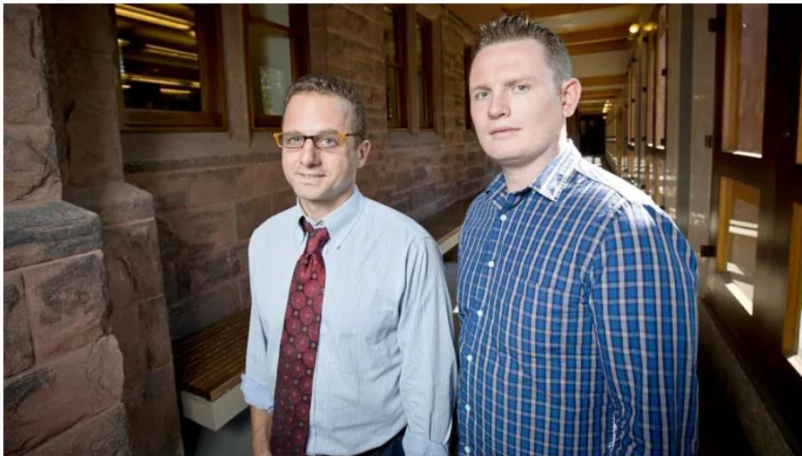
# 6. Risks to researchers

## How Alexander Sodiqov was freed following espionage charges



New chill for scholars in post-Soviet sphere hits University of Toronto student

Jennifer Clibbon · CBC News · Posted: Sep 23, 2014 5:00 AM ET | Last Updated: September 23, 2014



Edward Schatz, left, helped his doctoral student, Alex Sodiqov, right, get released by authorities in Tajikistan, where the University of Toronto student had gone to do academic research. (Evan Matsui/CBC)

149 comments

- U of T PhD student arrested in Tajikistan in June 2014 for espionage
- Was one day into a summer job interviewing Tajik civil society leaders for a British professor
- "They told me I was charged under article 305 of Tajikistan's criminal code [for treason and espionage] which carries a sentence of between twelve to twenty years. I felt, oh my God, I am going to spend my life in jail."
- #freealexsodiqov
- Prof Schatz used public pressure to gain his release

# Security and access concerns beyond the REB

Responsibility of principal investigator and institution to limit access to sensitive data

- Access due to department or team mishandling
  - Multi-lab access to one license
  - Forgetting to remove access when team members leave
- Unauthorized access through phishing emails to obtain passwords
- Research team members may have conflicts of interest\*
- Inadvertent access by friends, partners, family members who access shared devices
  - Particularly when work from home/ virtual schooling

British Columbia

# SFU ransomware attack exposed data from 250,000 accounts, documents show



Officials didn't disclose number in March when personal data of students, faculty, alumni were compromised



Alex Migdal

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# Ontario investigating potential security breach associated with COVID-19 vaccine portal



Katherine DeClerq CTV News Toronto Multi-Platform Writer

@KateDeClerq | Contact

Published Monday, November 22, 2021 11:13AM EST

Last Updated Monday, November 22, 2021 7:33PM EST

# Increased foreign threat to COVID-19 research prompts extraordinary warning from Canada's spy agencies



Warning comes a day after the U.S. intelligence agencies cited China-backed online attacks

Catharine Tunney · CBC News · Posted: May 14, 2020 3:57 PM ET | Last Updated: May 15, 2020



1153 comments

Canada's spy agencies are warning that Canadian intellectual property linked to the pandemic is a "valuable target" for state-sponsored actors — just a day after U.S. intelligence agencies warned of China-backed hacking of institutions and companies researching vaccines, treatments and tests for the novel coronavirus.

"The Communications Security Establishment has assessed that it is near certain that state-

# CSIS warns about China's efforts to recruit Canadian scientists

ROBERT FIFE > OTTAWA BUREAU CHIEF  
STEVEN CHASE > SENIOR PARLIAMENTARY REPORTER  
OTTAWA  
PUBLISHED AUGUST 6, 2020

PUBLISHED AUGUST 6, 2020

This article was published more than 6 months ago. Some information in it may no longer be current.

117 COMMENTS SHARE TEXT SIZE BOOKMARK



The Canadian Security Intelligence Service has warned the country's universities and research institutions that Beijing is using academic recruitment programs such as its Thousand Talents Plan to attract scientists to China in hopes of obtaining cutting-edge science and technology for economic and military advantage.

The federal spy agency says the Thousand Talents Plan (TTP), which Beijing created in 2008 to identify and recruit leading scientific experts around the globe, is an example of the way China is attempting to get academics to share – either

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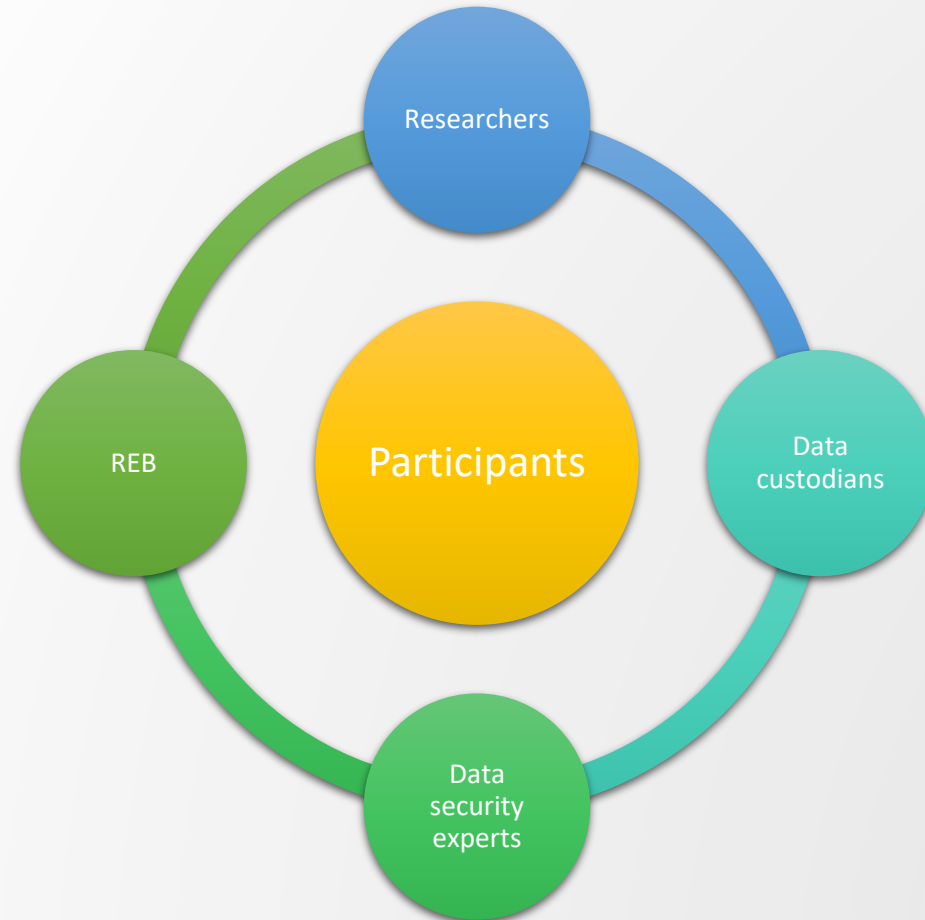
## Data security requires vigilance from all parties

- Do not rely on common sense; training is important
- Proper password hygiene
- Teach/re-teach/remind staff to
  - not open emails that look suspicious
  - hover over sender to see where email coming from
  - not click on links from unknown sources
  - Notify ITS if you receive a suspicious email
- Use MFAs correctly; do not click “yes” if receiving a push for MFA that you did not initiate
- If something seems suspicious, tell someone

# Data deposit and future use

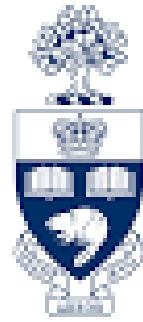
- REBs review projects, not data sets
- Appears to be a gap between REB, data custodians
  - Who ensures sensitive data are appropriately de-identified, protected?
  - Who ensures that projects involving deposited data sets have received REB review before acquisition?
- Solution may be part of implementing Tri-Agency policy on research data management
- Communication between data security professionals, data custodians, researchers and REB necessary

# Data security as a joint responsibility



# Summary

- Researchers conduct a significant breadth and depth of human research that involve collection, analysis and storage of sensitive data
- REBs use regulations, policies and understanding of risk to assess sensitivity of data and provide appropriate recommendations
- Recommendations may include considerations of what data will be collected and from whom, physical and electronic security measures
- These recommendations may not always be sufficient, and researchers need to be aware of potential risks to data security (and themselves), and be vigilant
- Data repositories and long-term storage are beyond the scope of the REB, requiring other roles to take ownership of data security issues
- Security of sensitive human research data is a joint responsibility between REBs, researchers, data custodians and data security experts



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# Optional assignment

Course on Research Ethics (CORE) tutorial:  
<http://tcps2core.ca/welcome>

TCPS 2: CORE  
Welcome

Panel on Research Ethics  
www.pre.ethics.gc.ca

More Information<sup>1</sup>  
Rollover Glossary<sup>2</sup>  
External Link<sup>3</sup>  
Internal Link<sup>4</sup> ↗

### TCPS 2: CORE — Tutorial


Assignment – Day 3

The online tutorial TCPS 2: CORE (Course on Research Ethics) is an introduction to the 2nd edition of the *Tri-Council Policy Statement: Ethical Conduct for Research Involving Humans (TCPS 2)*. It consists of eight modules focusing on the guidance in TCPS 2 that is applicable to all research regardless of discipline or methodology.

The purpose of TCPS 2: CORE is to provide an introduction to TCPS 2, primarily for researchers and, secondarily, for **REB**<sup>2</sup> members.

If this is your first time accessing TCPS 2: CORE, we suggest you click on the "CORE User Guide" for some tips on navigating the modules. There are also some other useful links below. Or you may go directly to the program by clicking the Log In button at right.


- CORE User Guide
- FAQ
- Acknowledgements
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