

# Privacy and Security for Research at Vancouver Coastal Health



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December, 2003



# Overview

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- Introduction to Privacy and Security at Vancouver Coastal Health
- BC Freedom of Information and Protection of Privacy Act (FOIPPA)
- Privacy and Security Considerations in Health Research
- Application for Data Access at VCH
- Some Things to Consider
- Bill Trott – Office of the Information and Privacy Commissioner of BC



# Privacy and Security at VCH

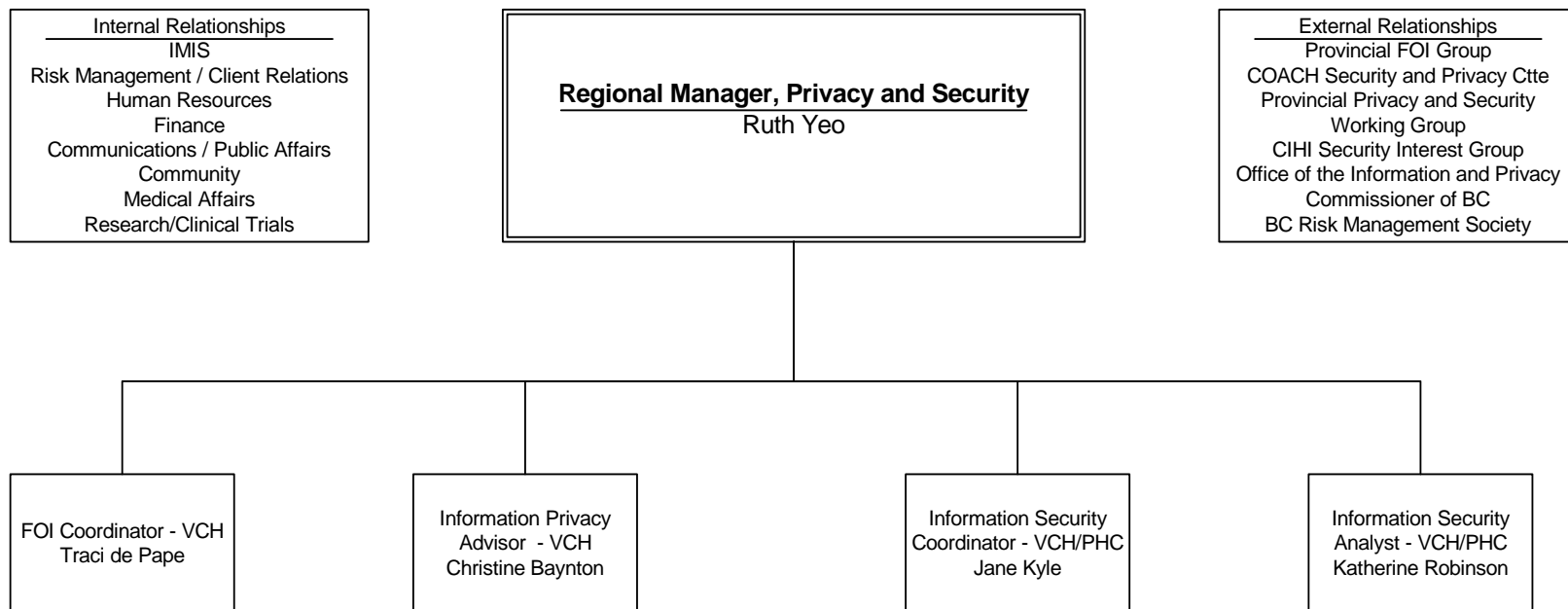
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- Established September 2002 to oversee:
  - Freedom of Information
  - Information Security
  - Information Privacy
- Shared Service Agreement with Providence Health Care



# Structure

## Information Management / Information Systems (IMIS) Privacy and Security





# What We Do

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- Freedom of Information – process non-clinical FOI requests; respond to complaints; point-of-contact for the public/media/unions; general release of information issues
- Information Security – auditing; data access requests; policies and procedures; risk assessments; incident/issues management; application security standards
- Information Privacy – privacy impact assessments; education and awareness initiatives; gap analysis; privacy issues



# Challenges

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- Internal:
  - High expectations
  - Competing priorities
  - Inconsistent policies
- External:
  - Patchwork of privacy legislation
  - Lack of standards, tools, guidelines
  - Inconsistency across health authorities



# Vision

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*“To protect individual privacy rights while balancing the need to share information appropriately in order to provide exceptional health care.”*



## BC Freedom of Information and Protection of Privacy Act (FOIPPA)

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- Provides specific information and privacy rights with regards to information that is collected or controlled by public bodies in BC
- Allows individuals to access their personal information and it protects their privacy by limiting the collection, use and disclosure of personal information
- As a public body, VCH is subject to the Act
- Researchers are bound by the provisions of the Act in addition to the organization's confidentiality policy



# What is Personal Information?

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- Any recorded information on an identifiable individual
- This can include, but is not limited to:
  - name, address, phone number, age, identifying number(s), fingerprints, blood type, health care history, education, financial, criminal or employment history
- Information could be recorded (stored) in any format or medium



# Section 35: Research

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- Outlines conditions regarding disclosure of personal information for research or statistical purposes
- A public body may disclose personal information for a research purpose if all four of the following conditions are met:
  1. The research cannot be reasonably accomplished unless the information is provided in individually identifiable form;
  2. Any record linkage is not harmful to the individual and the benefits are clearly in the public interest;
  3. The public body has approved conditions relating to: security and confidentiality; removal and destruction of individual identifiers at the earliest reasonable time; and the prohibition of any subsequent use/disclosure of information without the express authorization of the public body; and
  4. The researcher has signed an agreement to comply with the approved conditions, this Act, and any of the public body's policies relating to the confidentiality of personal information.



# VCH Responsibilities

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- Final responsibility in administering research agreements and is the final authority on approvals
- Must be satisfied that:
  - all four conditions are met
  - the recipient of the personal information will not disclose or share the information except as specified in the research agreement
  - adequate and reasonable security measures are in place to secure personal information from unauthorized access, disclosure, or theft etc.
  - research projects are not ongoing or “open –ended” but may be renewed as required



# Researchers' Responsibilities

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- Must complete and sign the Request for Approval to Conduct Research (appropriate signatures required for data access)
- Must complete and sign the Security & Confidentiality Review and Agreement for Access to Personal Information for Research Purposes (understanding of responsibilities under FOIPPA and corporate confidentiality policy)



# Privacy and Security Considerations in Health Research

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- Secondary Use of Information
- The Consent Debate
- Security Safeguards
- Privacy Impact Assessments



# Secondary Use of Information

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- Need for health research
- Need for access to data (secondary use)
- Need for privacy and confidentiality
- Balance the needs!



# The Consent Debate

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- Obtaining consent is not always practical!
- Retrospective and prospective studies
- Must ensure:
  - Open, transparent, accountable process for managing privacy
  - Confidentiality agreements are signed
  - Effective and strong safeguards in place to protect against unauthorized access, use and disclosure
  - Strong ethics review and research approval



# Security Safeguards

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- Organizational safeguards: ID badges, confidentiality acknowledgements, limited personnel access
- Physical safeguards: locked filing cabinets, doors, and facilities; anti-theft devices
- Technological safeguards: data encryption, passwords, audit trails



## Privacy Impact Assessments (PIAs)

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- A tool/template used to assess how a project or initiative impacts personal privacy
- Identifies risks associated with privacy *and* security and provides a mechanism for follow-up and mitigation
- PIA template available through the Privacy and Security Office



## Application for Data Access at VCH: Security & Confidentiality Review and Agreement

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- Outlines the security and confidentiality responsibilities and expectations to the Principle Investigator (PI)
- Ensures that security and confidentiality has been considered
- Completion and sign-off required for research approval



# Provisions for Personal Information

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- Will files containing personal information be kept in a locked filing cabinet?
- Will electronic storage be password protected?
- Will the room/premise be locked when not in use?
- Will only those authorized by the PI have access to the personal information?
- Will electronic files be encrypted for data transfer?
- Will you be contacting individuals to whom personal information relates?
- Will files, electronic and/or paper containing personal information be destroyed (when no longer needed)?



## Privacy and Security Approval Process

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- Follow-up and approval by the Privacy and Security Office within 24 hours of receipt (Monday to Friday 8-4pm or drop off in locked mailbox)
- Privacy and Security Office is located at Heather Pavilion B415



# Issues with Current Process

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- Concern with access to electronic data
- “Approval” for access allows the researcher to attend training to obtain a user login and password allowing them access to entire databases
- Many researchers have dual roles – as researcher and as care provider
- Access to electronic data could potentially be ‘unlimited’
- To think about for future discussions!



# Some Things to Consider

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- Think about the purpose of your research. Is every data element required? Is the data you are seeking access to really necessary? Can you justify your data needs?
- Think about the geographic scope of your research. Where will it be conducted? Within provincial borders? Or will it extend beyond provincial or national borders?



# More Things to Consider

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- Think about any commercial aspects of your research. Who is your employer? Who is funding you? Who are your partners? Will there be any economic gain or profit? Who are your data sources?
- Think about the long-term impact of your information practices on the trust and confidence of the data subjects and the public in general.



## Useful Resource: CIHR Publication - November 2002

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- Secondary Use of Personal Information in Health Research: Case Studies (November 2002)
- 19 real-life case studies
- Outline why each study is socially valuable, the benefits of the results, the kind of information researchers need and why, and how researchers collect, use and disclose data
- <http://www.cihr-irsc.gc.ca>



# Contact Information

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