Data Collection Best Practices

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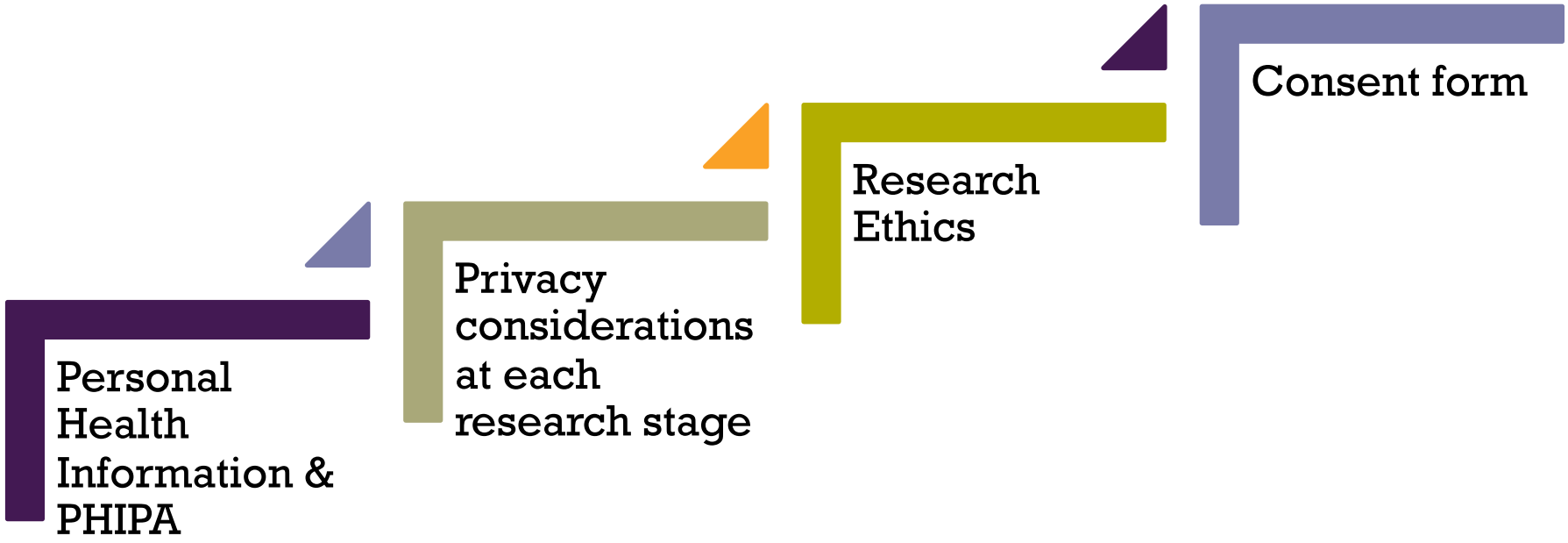
SCDAC

Overview

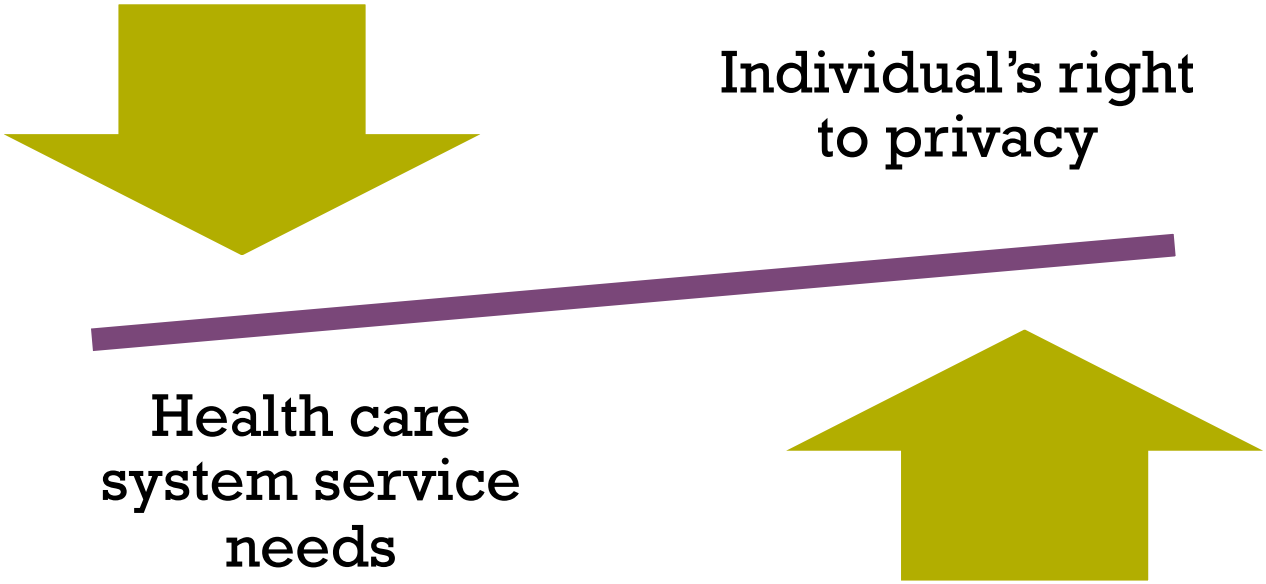

Personal Health Information & PHIPA
Privacy considerations at each research stage
Research Ethics
Consent form

Personal Health Information (PHI)

- Identifying information about an individual
- Any format: oral, paper, electronic, digital photos, etc.
- It reveals something of a personal nature about the individual
- Includes:
  - Medical history
  - Health care plan
  - Health care payments/eligibility
  - Relates to the donation of any body part or bodily substance or is derived from the testing or examination of any such body part or bodily substance

Personal Health Information Protection Act (PHIPA)

- Provincial legislation regarding the protection of PHI in Ontario
- Outlines privacy policies and practices for collecting, using, and sharing PHI



Key Points about PHIPA

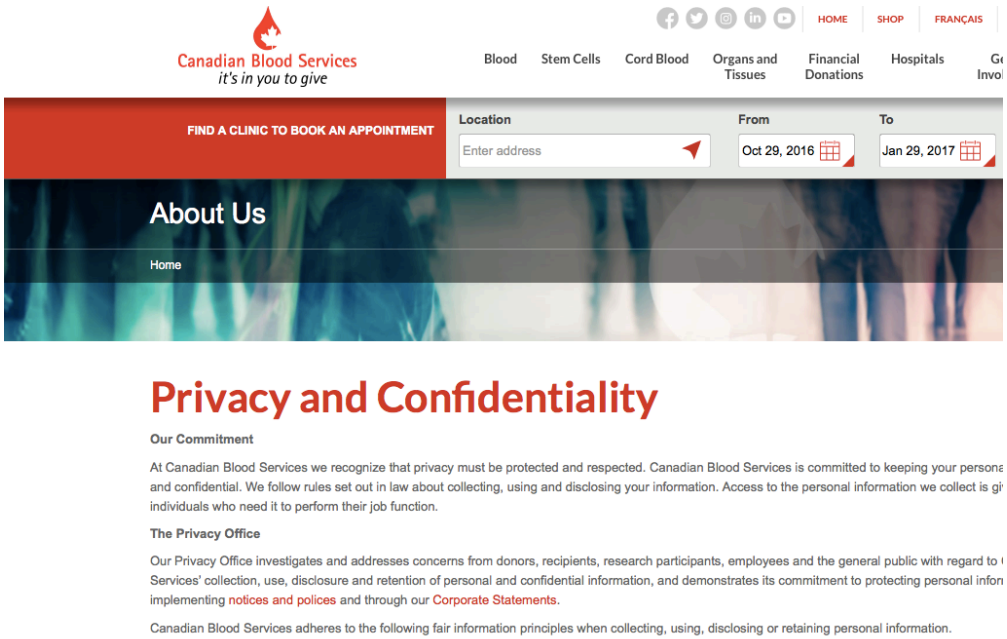
- Consent, and the right to withdraw consent
- Confidentiality and security of information
- Individual's right to their own PHI
- Rules and guidelines about how PHI is used:
  - Fundraising, marketing, research
- Complaint process → IPC (Information and Privacy Commissioner of Ontario)
- Legislation applies to **health information custodians**

Health Information Custodians

- Persons involved in delivering health care services
  - e.g. health care practitioners, hospitals, pharmacies, laboratories

- The Canadian Blood Services has been designated as a health information custodian

1. Accountability
2. Identifying Purpose
3. Consent
4. Limiting Collection
5. Limiting Use, Disclosure & Retention
6. Accuracy
7. Safeguards
8. Openness
9. Individual Access
10. Challenging Compliance
11. Privacy Office contact info



General Practices to Protect PHI

- Have policies and practices in place for using PHI
  - When, how, and for what purpose PHI is being collected, used, stored, and disclosed
- PHI should be protected from
  - Loss
  - Unauthorized use or disclosure
  - Unauthorized copying, modification, or disposal
- PHI should only be used for the purposes it was collected
- PHI records should be retained, transferred, and disposed of securely
- Individuals must be notified if their PHI is stolen, lost, or accessed by an unauthorized person

Consent

- An individual must give their consent regarding the collection, use, and discloser of their PHI
- Consent must be:
  - Knowledgeable, voluntary, and relevant
  - Information about how PHI is going to be used (collection, use, and disclosure) must be made easily available to individuals

Implied Consent	Express Consent
• Implied based on an action	• Consent has been **explicitly** given • Required for fundraising, research, and marketing/marketing research

Quick Recap …

- PHI: any personally identifying health information
- Governed by PHIPA, which balances the need to use PHI by service providers and the rights of individuals to privacy
- PHIPA covers the collection, use, and discloser of PHI
  - It also includes complaint process
- Consent: implied or express
- PHIPA applies to health information custodians
- General practices to protecting PHI
  - Having specific policies/procedures in place
  - PHI should be protected (unauthorized use, discloser, etc.)
  - Should be clear about how PHI is being used

Next…
Different Types of Research

Types of Research

	Research	Quality Improvement	Program Evaluation
Project Purpose	To generate new knowledge that is generalizable to the broader population	To improve processes, practices, or costs for a specific **intervention**	To inform decisions, identify improvements, and provide information about the outcome of a **program**
Scope	Generalized	Specific	Specific
How are findings used?	Increasing body of scientific knowledge	Change in specific practice/policy	Improve program design and implementation
Is REB required?	Yes	No	No

Adapted from: Department of Evaluation and Research Services, Fraser Health Hospital

Privacy Considerations

1. Survey Research Definition

- Clearly set out purpose and objectives
  - Will help limit the collection of data to what is truly necessary
- When collecting personal information, are required to inform the survey participant how their information is being used
- Information collected should only be used for the purpose it is being collected for
- **The only way to ensure complete confidentiality is to avoid collecting personal information or by conducting anonymous surveys**
- **Participation in survey research should always be voluntary**

2. Research Design

- Determine who will collect the data
  - Internal staff, external consultant, online survey provider*
  - Accountability for the stewardship of the data remains with the organization undertaking the survey research
- Minimize the collection of personal information
  - Determine if PHI is needed
  - Consider anonymous surveys if possible
    - Pre-addressed mail envelope (instead of an address)
    - Email the link (instead of using the online survey tool)
      - Use the BCC field
  - Use coded surveys
    - Two separate databases cross-referenced with the survey ID code
    - Coded surveys are still considered to be personal information
- Determine the most appropriate and least intrusive survey method
  - Telephone, email, paper survey?

*Using online survey providers

- **Online providers may allow third party tracking**
  - I.e., advertisements, widgets, website analytics, cookies
  - Avoid using an online survey provider that allows third parties to track survey participants
- **Online survey providers have their own Terms of Service and Privacy Policies that govern the collection of data**
  - Important consideration if personal information is being collected
- **Survey data may be stored outside of Canada**
  - Subject to foreign law
  - Consider using a self-hosting software program or application that can be installed on your organization's servers

Longitudinal Survey Research

- Surveys conducted with the same group of people over a period of time
- Agency staff may change over time
- Need to develop specific protocols for safeguarding participant information

Informed Consent

- Participating in survey research should always be voluntary
- Participants should always provide their informed consent
- Being informed means knowing:
  1. Who is conducting the research
  2. Why the research is being conducted
  3. How the information will be used
  4. How personal information will be protected
     (Including who will have access)
  5. How much time it will take
  6. Participation is voluntary, and questions can be skipped
  7. How participants can access the survey results
  8. Who to contact with any questions

3. Sample Selection

When using your agency's administrative data:

- Most times, only general information about clients will be used, such as name, address, telephone, or email
- But some surveys may call for a specific type of respondent based on age, gender, income, etc.
- Be clear about how you will be using your client's data, and that they may be contacted from time to time to be invited to participate in survey research

Best Practice: inform clients during intake that they may be contacted from time to time to participate in surveys, but that they can choose to opt out

4. Data Collection (Contacting Survey Participants)

- Consider your client's privacy when contacting them
  - **Mail**: do not use your agency's brand on the envelope
  - **Telephone message**: do not disclose personal information
  - **Cell phones**: consider that it may be answered in a public area
  - **Email**: consider emailing the link from your agency's email address (instead of the survey provider)

Analysis, Reporting, & Storing

5. Analysis

- Data collected through survey research should only be used for the purpose of that survey research
  - Participants consented to the use of their data for that purpose

6. Reporting

- Report results in aggregate
- Avoid reporting in specifics that could potentially identify an individual

7. Storage

- Keep data securely stored
- Consider using encryption and password protection
- Don't keep it longer than necessary

TCPS2

Tri-Council Policy Statement: Ethical Conduct for Research Involving Humans

- Updated in 2014

Key principles from the TCPS

- Respect for people (and their data)
- Need to especially consider surveying vulnerable populations and power dynamics
- Consent must be:
  - Voluntary: Free of coercion or pressure
  - Informed: Understand what they are consenting to
  - Ongoing: if study design changes
- The consent form should be stored separate from the data
- Participants must understand the foreseeable risks and potential benefits of participating

Key Points for Consent Form /1

- Purpose of the study
- Who is collecting the information and why
- Type of information being collected (confidentiality vs. anonymous)
- Foreseeable risks and potential benefits
- Contact information of the researcher
- Contact information of the relevant REB

Key Points for Consent Form /2

- Assurance that participation is voluntary and that participant can end their involvement at any time
- Sufficient prompts to encourage participants to ask questions
- Length of time it will take
- How information will be used and shared
- How participant can receive the results
- "I Consent" check box!

Resources

- Information and Privacy Commissioner of Ontario
  www.ipc.on.ca
- Office of the Privacy Commissioner of Canada
  www.priv.gc.ca
- Tri-Council Policy Statement: Ethical Conduct for Research Involving Humans
  www.pre.ethics.gc.ca
- Health Quality Ontario
  www.hqontario.ca
- Community Research Ethics Office (CREO)
  www.communityresearchethics.com