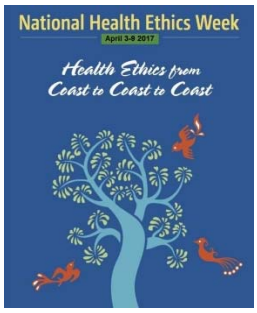

National Health Ethics Week 2017: April 3-9th

Research Ethics Bulletin #1: Privacy Best Practices

There is widespread agreement about the interests of participants in protection of privacy, and the corresponding duties of researchers to treat personal information in a confidential manner. Indeed, the respect for privacy in research is an internationally recognized norm and ethical standard. In Canada, this is recognized in the Tri-Council Policy Statement: Ethical Conduct for Research Involving Humans (TCPS2 2014).

Privacy risks in research relate to the identifiability of participants, and the potential harms they, or groups to which they belong, may experience from the collection, use and disclosure of personal information. Privacy risks arise at all stages of the research life cycle, including initial collection of information, use and analysis to address research questions, dissemination of findings, storage and retention of information, and disposal of records or devices on which information is stored. Below are some tips for protecting personal health information in the context of research.

Shared responsibility

- The protection of the privacy and confidentiality of all research participants and their information is the responsibility of all members of the research team;
- All members of the research team will be briefed on their responsibility for privacy protection;
- All members of the research team will sign an oath of confidentiality;
- Consequences for breach of confidentiality will be clearly stipulated to the research team.

Consider Privacy When Designing Research

- Follow the IT security and privacy policies established by your organization. Where these policies do not exist, it is recommended that they be established;
- Do not use small cell counts that could identify an individual (i.e., age groups may need to be categorized into 5 year intervals, community data may need to be categorized as Census Subdivision). This is particularly important in the dissemination of research results.

Consent

- Ensure all consent forms are accurate and up to date. Consent forms must include contact information if someone wishes to discuss privacy concerns or withdraw consent (e.g. a research ethics office who can address rights of research participants).

Collection

- Only collect the minimum amount of personal health information that is necessary to complete the research. Be prepared to provide justification for information that goes beyond a specific research objective.

Use

- Use information only for purposes that are identified in your consent form and approved by the research ethics board (REB).

Protection

- Encrypt personal health information at all times, including during transfer;
- Maintain physical data in a safe and secure location;
- If a third party is used to store data, ensure that privacy and confidentiality is maintained in accordance with the Personal Health Information Act (PHIA)[i].

Destruction

- Dispose data in accordance with the direction provided by the REB. Do not retain data any longer then is required by specified data retention periods.

Breaches

- When information is lost, stolen or accessed without authorization you must notify the organization from which you received the data and the Office of the Information and Privacy Commissioner (OIPC).

NEWFOUNDLAND AND LABRADOR HREA HEALTH RESEARCH ETHICS AUTHORITY

[i] PHIA sets rules for the protection of personal health information in Newfoundland and Labrador. More information may be found here: ***http://www.health.gov.nl.ca/health/phia/***