



TITLE	108: Uses and Disclosures of Personal Information (PI)
SCOPE	The activities of the Research Ethics Boards operating under the direct authority of the University of British Columbia
RESPONSIBILITIES	The Vice-President, Research & Innovation, delegated to the Director, Research Ethics, all Research Ethics Board (REB) Chairs and members, REB Office Personnel, and all UBC Researchers
APPROVAL AUTHORITY	The Vice-President, Research & Innovation
EFFECTIVE DATE	May 2018
Supersedes documents dated	June 2013; February 2009; July 2003

1.0 PURPOSE

The purpose of this standard operating procedure (SOP) is to describe the safeguards to protect the privacy of personal information, defined by the B.C. Freedom of Information and Protection of Privacy Act¹ as “recorded information about an identifiable individual other than contact information”, disclosed to the REB by faculty, staff and students of the various covered entities of the University of British Columbia.

The SOP provides guidance for the protection of information that:

- Is disclosed to the REB for the purposes of ethical review
- Arises during the review and approval processes, or
- Is related to the operation of the REB itself.

2.0 DEFINITIONS

See the Glossary of Terms.

3.0 PROCEDURE

It is the policy of the Office of Research Ethics at the University of British Columbia that personal information (PI) will be used and disclosed in a manner that respects individual's rights to privacy, and in accordance with federal and provincial privacy regulations and applicable laws².

The Researcher is responsible for submitting information to the REB and to the participant regarding the nature of the PI (including personal health information (PHI)) that will be collected for the research, including the manner in which it is identified, collected, accessed, used, disclosed, retained, disposed of and protected.

The University of British Columbia's Office of the University Counsel³ is responsible for providing Researchers and research staff with guidance on privacy policies and regulations.

Privacy is a fundamental value that is essential for the protection and promotion of human dignity. Breaches in privacy and confidentiality may cause harm to individuals or groups of individuals. Hence, PI must be collected, used and disclosed in a manner that respects a research participant's right to privacy, and in accordance with applicable federal and provincial privacy regulations.

Privacy regulations permit the use and the limited disclosure of PI for research purposes as long as certain requirements are met. One of the key ethical challenges for the health research community is in protecting appropriately the privacy and confidentiality of PI used for research purposes. The REB plays an important role in balancing the need for research against the risk of the infringement of privacy and in minimizing invasions of privacy for research participants. Individuals should be protected from any harm that may be caused by the unauthorized use of their PI and they should expect that their rights to privacy and confidentiality are respected.

3.1 REB Review of Privacy Concerns

3.1.1 The REB shall review the research submitted to determine if the Researcher has access to and/or is using personal information and whether appropriate British Columbia privacy legislation is adhered to;

3.1.2 In reviewing the research, the REB will include such privacy considerations as:

- The type of PI to be collected,
- The research objectives and justification for the requested personal data needed to fulfill these objectives,
- The purpose for which the personal data will be used,
- How the personal data will be controlled, accessed, disclosed, and de-identified,
- Limits on the use, disclosure and retention of the personal data,

- Any anticipated secondary uses of identifiable data from the research,
- Any anticipated linkage of personal data gathered in the research with other data about research participants, whether those data are contained in public or in personal records,
- Whether consent for access to, or the collection of personal data from participants is required,
- How consent is managed and documented,
- If and how prospective research participants will be informed of the research,
- How prospective research participants will be recruited,
- The administrative, technical and physical safeguards and practices in place to protect the personal data including de-identification strategies and managed linkages to identifiable data,
- How accountability and transparency in the management of personal data will be ensured;

3.1.3 The REB must find that there are adequate provisions to protect the privacy interests of participants before approving the research.

3.2 Receipt, Use, and Disclosure of Personal Information by the REB Office

3.2.1 The REB Chair, REB members and the REB Office Personnel are bound by confidentiality agreements signed prior to commencement of their duties;

3.2.2 REB members shall review UBC REBs policies on privacy and confidentiality and acceptable use of information systems and shall sign related acknowledgement/agreement forms;

3.2.3 The REB does not intentionally collect personal information;

3.2.4 The REB Chair, REB members and REB Office Personnel are permitted to receive personal information from a UBC entity and use or disclose such personal information for purposes necessary for the review, approval, ongoing monitoring and auditing of REB protocols;

3.2.5 The UBC Office of Research Ethics shall treat all information received from investigators as confidential and shall use or disclose such information only as necessary for the purpose of REB operations;

3.2.6 The UBC Office of Research Ethics must adopt reasonable safeguards to ensure that members of its workforce protect personal information from unauthorized access. REB Office Personnel who receive personal information for REB review activity shall not share such PI with any person, including any other member of the workforce of the REB itself or REB members, that does not require such PI for such activity.

- 3.2.7** The UBC Office of Research Ethics shall maintain and properly secure research files and other records related to REB operations, to ensure competent record-keeping and to avoid unintentional disclosures;
- 3.2.8** The UBC Office of Research Ethics shall arrange for copies of REB minutes and approved attachments to be distributed to authorized persons only⁴;
- 3.2.9** The UBC Office of Research Ethics shall ensure the confidential disposal/destruction of all confidential records related to review of research studies and other REB operations⁵;
- 3.2.10** Training on the policies and procedures set forth in this document will be provided for the existing REB Office Personnel, the REB Chair and the REB members to the extent applicable for their respective positions;
- 3.2.11** REB members or REB Office Personnel may consult with the REB Chair or designee if they are uncertain about the appropriate use or disclosure of personal information;
- 3.2.12** The REB Chair will ensure that reports to researchers on REB decisions do not contain any personal identifiers of individual reviewers;
- 3.2.13** In the event that a Principal Investigator is invited to attend an REB meeting to address questions about his/her research application, ensure the Principal Investigator attends only that portion of the meeting necessary to address his/her concerns. A Principal Investigator cannot attend the reviewer's presentation, the vote or discussion of any study, including his/her own;
- 3.2.14** The REB Chair, in collaboration with REB Office Personnel, the Privacy Officer of the institution, the Director, Office of Research Ethics, and any other applicable Institutional Officer, shall manage all requests for release of documents that are under the custody and/or control of the REB;
- 3.2.15** If any personal information is received inadvertently in the REB office (e.g. disclosed by a Researcher), appropriate notification must take place and any corrective action that is required including, if applicable, notification to the appropriate Organizational Official. The facts surrounding the breach, the appropriate steps taken to manage the breach, remedial activities to address the breach and the outcome will be documented. The personal information will be destroyed in a secure manner as per the University of British Columbia policies and procedures;
- 3.2.16** If there is an internal breach involving the use or dissemination of personal information, the REB Chair or designee will be notified, and if applicable, notification of the appropriate Organizational Official, and a determination will be made in a timely manner regarding a corrective action plan. This process may include notification, containment, investigation and remediation, and strategies for prevention. The facts surrounding the breach, the appropriate steps taken to manage the breach and the

outcome will be documented. The personal information will be destroyed in a secure manner as per the University of British Columbia policies and procedures;

3.2.17 At the discretion of the REB Chair or designee, in consultation with the organization, the British Columbia provincial privacy office (or equivalent) may be notified.

4.0 REFERENCES

1. *Freedom of Information and Protection of Privacy Act, British Columbia:*

http://www.bclaws.ca/civix/document/id/complete/statreg/96165_01

2. *Personal Information Protection and Electronic Documents Act:*

<http://laws-lois.justice.gc.ca/eng/acts/P-8.6/>

3. *The University of British Columbia Office of the University Counsel:*

<http://universitycounsel.ubc.ca/access-and-privacy/>

4. *UBC Policy 106:*

http://nqueryrpts.finance.ubc.ca/documents/policies/Access_to_and_Security_of_Administrative_Info.pdf

5. *UBC Policy 117:*

<http://universitycounsel.ubc.ca/files/2010/08/policy117.pdf>