



### Electronic Submissions Of Applications

[www.sfu.ca/~dore/](http://www.sfu.ca/~dore/)

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Office of Research Ethics

[www.sfu.ca/vp-research/ethics](http://www.sfu.ca/vp-research/ethics)

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SFU Policy R20.01: Ethics Review of  
Research Involving Human Subjects

[www.sfu.ca/policies/research/r20-01.htm](http://www.sfu.ca/policies/research/r20-01.htm)

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### *Thesis Submissions*

The procedure for documentation of ethics approval to the Library when submitting a thesis is the following: Students submit a copy of the original ORE letter of approval for the project to the Library. When the thesis is part of a collaboration with a project of a senior supervisor who is the Principal Investigator (PI), the approval letter to the PI will show the student as a collaborator. It is important that all collaborators be identified by the PI at the time of application or as a later amendment to the application. Amendments must be made by the PI.

### *Deadlines For Course Applications*

Applications for the approval of courses as a "Research Ethics Board Approved Course" under Policy R20.01-6.3 is:

Summer Semester	April 1
Fall Semester	August 1
Spring Semester	December 1

### *Sub-Grant Agreements*

There has been an increasing number of grants to faculty that have both national and international components. Frequently these components may involve sub-grants by the Principal Investigator at SFU that requires the transfer of funds from SFU to other institutions or agencies for a component of the research. In some cases the recipient of the sub-grant does not have an ethics board or policy that has been recognized and approved by SFU or the Tri-Council. In such cases the REB of SFU has agreed to the format of an agreement between SFU and the agency that is the recipient of the sub-grant. This agreement includes the following statement:

Responsibilities of the UNIVERSITY (the university or the agency receiving the sub-grant): The UNIVERSITY agrees to comply with all regulations set forth in the Tri-Council Policy of Canada (URL is identified) including assurances that any and all required human ethics approvals have been met where applicable. The parties acknowledge that, further to these regulations, the Research has been reviewed and approved by SFU's Research Ethics Board. The UNIVERSITY agrees to comply with all requirements and requests of SFU's Research Ethics Board regarding the conduct of the Research, and the UNIVERSITY further agrees to provide proof of such compliance upon request by SFU which includes an annual report on ethics research, and reporting and approval of any and all changes in protocol prior to their usage in the Research.

The REB of SFU has agreed to adopt the statement as an internal policy for the approval of sub-grants if a recognized ethics board or procedure is not available to the sub-grant collaborator.

## *Education*

If you would like the Office of Research Ethics to give a talk to students about policy or process, or discuss specific issues, please email the request to [dore@sfu.ca](mailto:dore@sfu.ca).

Powerpoint presentations are available on disk for instructors or students who wish copies. Contact [dore@sfu.ca](mailto:dore@sfu.ca) for access to the disks or access the web site: [www.sfu.ca/vp-research/ethics/training.html](http://www.sfu.ca/vp-research/ethics/training.html).

## *Recent Internal REB Policies*

Any amendments to a protocol which has been designation as non-minimal risk, must come to the REB for full review.

If a protocol is approved which does not require written consent, a record must be kept of whom the researcher has interviewed, or who has participated.

The opinion of the Director of the Office of Research Ethics should be sought whenever there is doubt whether or not a particular research project requires ethics review.

The REB may give approval to generic unspecified projects within a course but will not give approval to multiple courses in the same application. Each course is considered and evaluated individually.

Oral history research should be treated like any other form of human subject research and consequently is subject to ethical approval.

Projects using secondary data must include acceptable consent procedures in the protocol of the original project, which included the possibility of use of the data in the way in which the current application for secondary use proposes, unless the data is in the public domain.

If students are approached or tested on school grounds, permission of the school district is required.

When a graduate or undergraduate student is shown as the principal investigator of an application, the supervisor of the student is always the coinvestigator.

## *The U.S. Patriot Act*

Several sections of the U.S. Patriot Act permit American authorities to ask for secret court orders to allow them to gather information about individuals, and which permit the FBI to issue “national security letters” compelling companies to secretly disclose personal information without informing individuals or agencies that such disclosure has occurred.

A report of the British Columbia Office Of Information and Privacy Commission (Oct. 2004) entitled “Privacy Implications Of The USA Patriot Act” recommends “Because there is a ‘reasonable possibility’ of unauthorized disclosure of British Columbians’ personal information under the USA Patriot Act, ‘rigorous other measures must be put into place to mitigate against illegal and surreptitious access’. The report recommends that legislation should be passed to make it an offence for a public body or a contractor to disclose personal information or send it outside Canada in response to a foreign court order, subpoena or warrant, with violation being punished by a fine of up to \$1 million or a term of imprisonment, or both, and that public bodies should be required to ensure that outsourcing contracts contain provisions designed to preclude control by a US company over records containing British Columbians’ personal information.

The report further recommends that legislated controls should be passed to deal with information sharing and data mining activities, in order to better protect privacy and ensure transparency around these activities.

The BC government passed Bill 73 that was intended to deal with the issue. “unauthorized disclosure of personal information” means disclosure of, production of or the provision of access to personal information to which this Act applies, if that disclosure, production or access is not authorized by this Act”.

## *U.S. Patriot Act (continued)*

1. (a) demands from a foreign court, an agency of a foreign state or another authority outside Canada, and (b) demands for the unauthorized disclosure of personal information to which this Act applies. 2. If a public body, an employee of a public body or an employee or associate of a service provider (a) receives a foreign demand for disclosure, (b) receives a request to disclose, produce or provide access to personal information to which this Act applies, if the public body, employee or other person receiving the request (i) knows that the request is for the purpose of responding to a foreign demand for disclosure, or (ii) has reason to suspect that it is for such a purpose, or (c) has reason to suspect that unauthorized disclosure of personal information has occurred in response to a foreign demand for disclosure, the head of the public body, the employee or other person must immediately notify the Minister responsible for this Act.(3) The notice under subsection (2) must include, as known or suspected, (a) the nature of the foreign demand for disclosure, (b) who made the foreign demand for disclosure,(c) when the foreign demand for disclosure was received, and (d) what information was sought by or disclosed in response to the foreign demand for disclosure.

The BC Privacy Commissioner, David Loukidelis pointed out that U.S. courts have upheld orders requiring corporations to disclose records outside of the U.S., even when foreign law prohibits such disclosure. This means that there is no guarantee that companies that are Canadian subsidiaries of U.S. companies are not required to comply with the Patriot Act.

Consequently, the internal policy of the Simon Fraser University REB is to require projects that transmit information to U.S. collaborators be anonymous, and that companies contracted to collect or analyze personal data that is collected by email or through the internet not be a company registered in the United States.

## *Secondary Data and Database Use*

The term Secondary Data here refers to the use of data that has been previously collected and is not in the public domain. In many cases this data is in the form of a database. There are several issues of the following types that arise in the consideration of applications for the approval of the use of secondary data: (a) When the data was originally collected did individuals give consent, (b) If consent was given is the intended use of the data as secondary data consistent with the original consent, (c) If consent was given and the intended use of the data is not consistent with the original consent is it nevertheless acceptable if the data is anomalous, (d) If the data is anonymous but relates to communities, like aboriginal communities, and the intended use is not consistent with the original purposes of the study, can the data be used without approval of those communities?

Currently the REB evaluates these applications on a case-by-case basis, however, the way in which to systematically deal with secondary data is now under discussion. The current position of the REB is that the use of the database has to be consistent with the original intent of its use when consent was given, regardless of whether the data is anonymous.

This issue is particularly important in the use of many database collection of information that is shared by multiple laboratories. Some of these database collections are owned by public and private agencies. In these cases the question also arises as to whether the REB should accept the approval of the owners of the database regardless of other principles with respect to its use.

The argument has been made that if anonymity is preserved then there should be unencumbered use of the data if it is released by its owners.

## *Implicit Consent*

The Personal Information and Protection Act of British Columbia defines and allows implicit consent as follows.

8 (1) An individual is deemed to consent to the collection, use or disclosure of personal information by an organization for a purpose if (a) at the time the consent is deemed to be given, the purpose would be considered to be obvious to a reasonable person, and

(b) the individual voluntarily provides the personal information to the organization for that purpose.

(2) An individual is deemed to consent to the collection, use or disclosure of personal information for the purpose of his or her enrollment and coverage under an insurance, pension, benefit or similar plan if he or she is a beneficiary or has an interest as an insured under the plan.

(3) An organization may collect, use or disclose personal information about an individual for specified purposes if

(a) the organization provides the individual with a notice, in a form the individual can reasonably be considered to understand, that it intends to collect, use or disclose the individual's personal information for those purposes,

(b) the organization gives the individual a reasonable opportunity to decline within a reasonable time to have his or her personal information collected, used or disclosed for those purposes,

(c) the individual does not decline, within the time allowed under paragraph (b), the proposed collection, use or disclosure, and

(d) the collection, use or disclosure of personal information is reasonable having regard to the sensitivity of the personal information in the circumstances.

(4) Subsection (1) does not authorize an organization to collect, use or disclose personal information for a different purpose than the purpose to which that subsection applies.

## *Research Ethics Board*

### **Faculty Members:**

Dr. Bruce Whittlesea (Chair), *Psychology*

Dr. Charles Krieger, M.D., *Kinesiology*

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Dr. Lynne Quarmby, *Molecular Biology*

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Dr. Felix Breden, *Biological Sciences*

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### **Student Members:**

Mr. Spencer McGrath, *Molecular Biology*

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Mr. William Melville

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### ORE News

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