



**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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*Deadlines For Course  
Applications*

Applications for the approval of courses as a  
“Research Ethics Board Approved Course” un-  
der Policy R20.01-6.3 is:

Summer Semester    April 1

Fall Semester        August 1

Spring Semester     December 1

*Data From Employees of  
Companies Or Agencies*

The following is a policy of the REB:

Whether a signed consent is or is not used the  
participant(s) must be advised that employers,  
and/or government authorities have, when ap-  
plicable:

- 1.)    Given permission
- 2.)    Denied permission
- 3.)    Not been approached for permission.

Before the researcher can conduct research with  
employees, participants must be warned if per-  
mission has not been sought from the employer  
for their employees to take part in the study.

*Studies of Human Genetics:  
Recommendations of the World  
Health Organization*

The following are a summary of the recom-  
mendations by the World Health Organization.  
For the complete document refer to:  
[http://www.law.ed.ac.uk/ahrb/publications/on-  
line/whofinalreport.pdf](http://www.law.ed.ac.uk/ahrb/publications/on-line/whofinalreport.pdf)

Recommendation 1: The World Health  
Organisation should investigate the issues  
raised by genetic databases from perspectives  
other than that which reflects a western, Judeo-  
Christian ethic.

Recommendation 2: The intimate and unique  
relationship that individuals have with body  
samples or information derived from them  
deserves full recognition and proper respect.  
Individuals are entitled to control over the use  
of their samples and information, in a manner  
akin to a property right. This right may,  
however, be subject to waiver or certain limits,  
such as when anonymisation occurs (and so  
the relationship is lost), or when certain uses  
may cause harm to others.

Recommendation 3: The collection of genetic  
data should only be allowed, in the first  
instance, for the purpose of promoting public  
health. The onus is on those who would seek  
to use data outside this purpose to justify doing  
so. Whatever the reasons for the establishment  
of a genetic database, the onus will be on those  
who seek to create the database to justify its  
nature, purposes, content and uses.

Recommendation 4: It is recommended that an  
appropriate ethical approval mechanism be  
established to oversee the creation and  
maintenance of genetic databases.

Recommendation 5: Public debate should precede the establishment of new genetic databases. A database should not be established in the shadow of wide-spread public unease. Adequate mechanism to gain public trust must also be set in place. No database should be established if public trust is seriously in doubt.

Recommendation 6: When obtaining informed consent to the provision of a sample or information for a genetic database, participants should be informed to the following extent:

- (1) Participants should be given sufficient information to make a meaningful choice about participation in research leading to the establishment of a database, including information about the purposes of the database and its commercial potential;
- (2) Sufficient information should be provided to ensure that participants comprehend the nature of the enterprise to their own satisfaction;
- (3) Participants should be given the opportunity to ask questions and have these answered;
- (4) Participants should be informed of the risks of participating, where these exist;
- (5) Participants should be informed of the security provisions that exist to protect their personal data;
- (6) Participants should be informed of the alternatives to participating, and in particular, should receive assurances that no adverse consequences will follow if they choose not to participate;
- (7) Participants should be informed of the uses to which data might be put, including potential use to avoid harm to third parties, such as blood relatives;
- (8) Participants should be informed of the possibility of future uses of data, beyond the limits of the present consent, and should be provided with an opportunity to withhold consent to such uses.

Recommendation 7: While the use of anonymisation can lead to a re-assessment of the balance between the protection of individual interests on the one hand, and the legitimate pursuit of

public interests on the other, it is recommended that any anonymisation process be overseen by an independent body.

Recommendation 8: While, normally, genetic research data will remain of abstract significance, in limited circumstances data may be of value in a clinical setting. This use of data is permissible when:

- (a) the data have been instrumental in identifying a clear clinical benefit to identifiable individuals;
- (b) the disclosure of the data to the relevant individuals will avert or minimise significant harm to those individuals;
- (c) there is no indication that the individuals in question would prefer not to know.

Recommendation 9: Blanket consent for future research is only permissible in circumstances where anonymity of future data can be guaranteed.

Recommendation 10: Research using archival material, such as pre-existing health records, specific health disorder databases or physical samples that have been retained - for which no specific consent has been obtained - is only permissible if the material and information derived from it is anonymised, and there is no prospect that research results will be used to identify the sample sources at any future time.

Recommendation 11: Research using samples or genetic information taken from vulnerable subjects, such as incapacitated adults or children, must be carried out in full conformity with internationally agreed principles and guidelines.

Recommendation 12: The taking of samples or generation of genetic information for research purposes must respect the child's confidentiality and must only be undertaken with the explicit approval of a competent research ethics committee.

Recommendation 13: Death of a sample source only affects the primacy of his/her interests, it does not extinguish them. Other interests, such as those of researchers or family members (including future family members) remain valid. If it is thought appropriate to readjust the balance of interests in light of death, then appropriate ethical approval should be sought to do so.

Recommendation 14: Those who would seek to depart from the practice of requiring active informed consent prior to participation in the creation of a genetic database must justify this position in strong ethical terms. As a minimum the following criteria must be satisfied: (a) a clear, realisable and significant public health benefit must be identified, (b) the widest possible educational programme must be instituted among the population that will participate, including an opportunity for public debate (c) strong privacy protection measures must be implemented, (d) individuals must at all times be given the opportunity to refuse to participate, and (e) every stage of the process must be subject to the most stringent ethical scrutiny.

Recommendation 15: The gathering and storage of genetic samples and information must be subject to rigorous privacy protection measures and in conformity with international and national data protection laws. These privacy measures must be transparent and subject to ethical approval by a suitable body.

Recommendation 16: Adequate account must be taken of the privacy interest that individuals have in not knowing information about themselves.

Recommendation 17: It should be the role of an independent body to oversee and regulate access to genetic databases. This same body should hold the key to any anonymisation methods that have been used.

Recommendation 18: Personally identifiable information held on a database should be subject to adequate subject access rights, in line with existing international measures. This information, and any personally identifiable samples also held, should be destroyed on the request of the subject. This provision is not waivable by consent, except where absolute anonymity is guaranteed. In other cases, this request must be complied with unless the holder of the information or the sample can show that it is not reasonably practicable to do so.

Recommendation 19: Serious consideration should be given to recognising property rights for individuals in their own body samples and genetic information derived from those samples. In all circumstances, the provision of research materials, including DNA samples, should be on the undertaking that some kind of benefit will ultimately be returned, either to the individual from whom the materials were taken, or to the general class of person to which that individual belongs.

Recommendation 20: The establishment, maintenance and operation of genetic databases should be carried out in an atmosphere of openness, transparency and appropriate ethical scrutiny. While it is accepted that in certain cases commercially sensitive data derived from a database can be kept confidential, more consideration is required of the precise circumstances in which this will be permissible. It will never be permissible if this would seriously prejudice the interests of individuals who have contributed samples or information to the database.

## *Application Procedure*

Note: Electronic applications are required and paper copy will not be accepted except under unusual circumstances.

1. Applicants send an email to the Office of Research Ethics (dore@sfu.ca) requesting a code for the purpose of accessing on-line forms. Include a project title, your name, department or school within SFU, and if applicable, your supervisor's name and short form e-mail address (dore@sfu.ca, not jane\_dore@sfu.ca).

2. The Office of Research Ethics answers your email with a code and the web site address of the forms.

3. After completion of each form it is submitted as shown on each form.

4. When you have completed all forms that are to be submitted you send an email to dore@sfu.ca with the title and THE PASSWORD ASSIGNED TO YOU indicating that the electronic application is complete.

5. After the application has been reviewed the disposition of the application will be sent to your email address in pdf format.

6. If students are applying for ethics approval the student's supervisor will be sent Form 1 and disposition of the application by email and asked to confirm that he or she has approved the application.

7. The Office of Research Ethics will close web access to your forms.

8. An approval letter will be sent by Campus Mail to your Department or School.

## *Research Ethics Board*

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### ORE News

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