

## **Guidelines for Secondary Use of Data (REB Approved - July 2001)**

The primary researcher(s) has (have) exclusive right to use data collected in any study for the period of time that is required for her/him to complete her/his research study. Thereafter, the researcher is encouraged to make such data available to other scholars, including graduate students, who may re-analysis the data or replicate the study of the primary researcher. Normally such secondary access to the data will not include access to any personal identifiers.

### **Definition of Secondary Use of Data:**

Researchers are encouraged to review Section 3 (Privacy and Confidentiality), Clauses C (Secondary Use of Data) of the Tri-Council Policy Statement (TCPS) prior to embarking on any research that involves secondary use of data.

"Secondary use of data refers to the use in research of data contained in records collected for a purpose other than the research itself. Common examples are ... school records ..., originally produced ... educational purposes, but now proposed for use in research. This issue becomes of concern only when data can be linked to individuals, and becomes critical when the possibility exists that individuals can be identified in the published reports." (TCPS, 3:C)

The Brock REB has extended this definition to include a third party's access to research data collected by one research or research team for a purpose that was not originally identified in the research protocol or consent processes. Such third parties may include graduate or senior undergraduate students who desire to use such data for theses or research papers or colleagues, whether at Brock, another university, or public agency.

### **Procedures:**

The Brock REB requires ethics review of all research protocols/studies that include the use of secondary data, especially where identifying information is involved (TCPS, Section 3:B and Section 3:C, Article 3.3).

The Brock REB will allow researchers to access identifying information if they demonstrate that:

- Identifying information is essential to the research; and
- They will take appropriate measures to protect the privacy of the individuals, to ensure the confidentiality of the data, and to minimize harms to subjects;
- Individuals to whom the data refer have not objected to secondary use.

The Brock REB may also require that a researcher's access to secondary use of data involving identifying information be dependent on:

- The informed consent of those who contributed data or of authorized third parties; or
- An appropriate strategy for informing the subjects; or
- Consultation with representatives of those who contributed data. (Article C:3.4)

The Brock REB may require full board review "in highly sensitive situations such as when identifiable data will be published or other instances when there is a significant risk of breach of confidentiality." In such cases the REB may require the researcher/research team "to seek consent to use the stored data from those who made the contribution."

The Brock REB recognizes that it may be "difficult or economically unfeasible to contact all subjects in a study group to obtain informed consent. This can occur when the group is large or its members are deceased, geographically dispersed or difficult to track." It is the obligation of the researcher/research team to identify ways in which the rights of the participants and the confidentiality of their information will be maintained.

**Expedited Reviews:**

Where research protocols/studies involve the secondary use of data that does not include any identifying information and where risk to research participants is considered minimal, the REB review can be expedited.

**Data Linkage:** (See Articles C:3.3 and D:3.6)

Researchers should pay particular attention to the use of data bases and be sensitive to the possibility of identifying individuals through data bases. The REB is required to "appraise the possibility of identification, in particular with regard to the extent of the harm or stigma which might be attached to identification. The REB and the researcher should also be aware of legal provisions that affect the database(s) to be used in the research."

The Brock REBs requires that researchers identify the "context in which the database was created, such as a confidential relationship, and ... the expectations of the groups or individuals at the time of the collection of the data with regard to its use, retention and disclosure."

**Re-contacting research participants:**

Researchers who wish to contact individuals to whom data refer shall seek the authorization of the REB prior to contact. The researcher must provide compelling reasons why follow-up contact and/or interviews with former study participants is required. (See Article C:3.5.)