

PRIVACY AND CONFIDENTIALITY

Section:	Academic/Student (AC)
Subject:	Applied Research
Legislation:	<i>Freedom of Information and Protection of Privacy Act (RSA 2000 cF-25).</i>
Effective:	January 21, 2005
Revision:	January 20, 2006; January 29, 2013; September 1, 2016 (reformatted)

APPROVED: _____
President and CEO

POLICY

The policy of the Board of Governors is to establish principles that promote and facilitate the conduct of all research in ways that respect human dignity and that demonstrate concern for the welfare of living human research participants, in accordance with national human research ethics policies.

PROCEDURE

DEFINITIONS

- Confidentiality** The obligation of an individual or organization to safeguard entrusted information.

- Data linkage** The merging or analysis of two or more separate data sets (for example, health information and education information about the same individuals) for research purposes.

- Identifiable information** Information that may reasonably be expected to identify an individual, alone or in combination with other available information.

- Principal investigator** The lead investigator completing the research.

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Privacy	An individual's right to be free from intrusion or interference by others. Individuals have privacy interests in relation to their bodies, personal information, expressed thoughts and opinions, personal communications with others and the spaces they occupy.
Research Ethics Board (REB)	The board that reviews research applications to ensure that researchers comply with this procedure.
Researcher	Any member of the SAIT community or any person external to the SAIT community who conducts or carries out research using SAIT resources and/or formally using members of the SAIT community as human participants. This includes but is not limited to researchers carrying out scholarly activity, applied research, and/or research under the terms of a Cadmus Trades Teaching Chair award or a Cisco e-Learning Chair award.
Secondary use of data	The use of research for a purpose other than the purpose for which it was originally collected. Common examples are social science or health survey datasets collected for specific research or statistical purposes but then re-used to answer other research questions. It also refers to situations where data was obtained for one REB-approved project, but is subsequently proposed to be used in new research.
Security	Measures used to protect information. It includes physical, administrative and technical safeguards.

PROCEDURE

1. Researchers may seek to collect, use, share and access different types of information about participants. Such information may include personal characteristics or other information about which an individual has a reasonable expectation of privacy (for example, age, ethnicity, educational background, employment history, health history, life experience, religion and social status).
2. Researchers and the Research Ethics Board (REB) shall consider whether information proposed for use in research is identifiable. The following categories provide guidance for assessing the extent to which information could be used to identify an individual:

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- a) Anonymized information: the information is irrevocably stripped of direct identifiers, a code is not kept to allow future re-linkage, and risk of re-identification of individuals from remaining indirect identifiers is low or very low.
 - b) Anonymous information: the information never had identifiers associated with it (for example, anonymous surveys) and risk of identification of individuals is low or very low.
 - c) Coded information: direct identifiers are removed from the information and replaced with a code. Depending on access to the code, it may be possible to re-identify specific participants (for example, the principal investigator retains a list that links the participants' code names with their actual name so data can be re-linked if necessary).
 - d) Directly identifying information: the information identifies a specific individual through direct identifiers (for example, his/her name, social insurance number, personal health number, etc.).
 - e) Indirectly identifying information: the information can reasonably be expected to identify an individual through a combination of indirect identifiers (for example, date of birth, place of residence or unique personal characteristics).
3. Researchers shall safeguard information entrusted to them and not misuse or wrongfully disclose it.
 4. SAIT shall support its researchers in maintaining promises of confidentiality. Where possible, participants must be guaranteed privacy and anonymity, and their responses must be treated with confidentiality. If anonymity and confidentiality cannot be assured or granted, potential participants must be made aware of the limitations and of the possible consequences before they are asked for their consent to participate.
 5. Researchers who intend to interview a participant to secure identifiable personal information shall obtain REB approval for the consent and interview procedures used and shall ensure the free and informed consent of the respondent as required in procedure [AC.4.4.2 Free and Informed Consent](#). For the purposes of this sub-section, interview includes face-to-face, telephone or other electronic encounters and individualized questionnaires which the researcher may use to gather personal information about participants. REB approval is not required for access to publicly available information or materials, including archival documents and records of public interviews or performances.
 6. Researchers shall describe measures for meeting confidentiality obligations and explain any reasonably foreseeable disclosure requirements in application materials they submit
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to the REB and during the consent process with prospective participants. Researchers shall provide details to the REB regarding their proposed measures for safeguarding information, for the full life cycle of information: its collection, use, dissemination, retention and/or disposal.

7. Researchers who have not obtained consent from participants for secondary use of identifiable information shall only use such information for these purposes if the REB is satisfied that:
 - a) Identifying information is essential to the research;
 - b) The use of identifiable information without the participants' consent is unlikely to adversely affect the welfare of individuals to whom the information relates;
 - c) The researchers will take appropriate measures to protect the privacy of individuals, and to safeguard the identifiable information;
 - d) The researchers will comply with any known preferences previously expressed by individuals about any use of their information;
 - e) It is impossible or impractical to seek consent from individuals to whom the information relates; and
 - f) The researchers have obtained any other necessary permission for secondary use of information for research purposes.
8. When secondary use of identifiable information without the requirement to seek consent has been approved, researchers who propose to contact individuals for additional information shall, prior to contact, seek REB approval of the plan for making contact.
9. Researchers who propose to engage in data linkage shall obtain REB approval prior to carrying out the data linkage, unless the research relies exclusively on publicly available information.
10. The application for approval shall describe the data that will be linked and the likelihood that identifiable information will be created through the data linkage. Where data linkage involves or is likely to produce identifiable information, researchers shall satisfy the REB that the data linkage is essential to the research and that appropriate security measures will be implemented to safeguard information.

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POLICY/PROCEDURE REFERENCE

- AC.4.4 Human Research policy
- AC.4.4.1 Research Requiring Ethics Review procedure
- AC.4.4.2 Free and Informed Consent procedure

PROCEDURE

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