**RYERSON UNIVERSITY**

**Research Ethics Board Guideline**

**Confidentiality and Anonymity**

**Purpose**

The purpose of this guideline is to help researchers understand the need to maintain confidentiality of participants’ identities, participant’s personal information, the requirements of protection of privacy and the difference between confidentiality and anonymity.

In most research studies, maintaining confidentiality is the norm. If there are special situations in which participants’ confidentiality can or will not be maintained, they must be made aware of this during the consent process.

**Definitions**

The terms “confidentiality” and “anonymity” are often misunderstood when discussing research.

Confidential research refers to research studies in which the researcher knows the identity of the participants and has strategies in place to not disclose participants’ identities or opinions. If, as a researcher, you know the identities of your participants, then you cannot refer to “anonymity” in the research project, but simply note that you are “maintaining confidentiality”

Research can only be referred to as anonymous when the participants are completely unknown and unidentifiable, even to the researcher. Data may be made anonymous (“anonymized”) by removing all identifiers from the data and removing the link between anything identifiable and the data so that a link cannot be established between the data and identities of participants. When anonymized, even the researcher will not be able to link the data with a participant.

**Requirements**

The general rule in research is that confidentiality cannot be breached without the participant's consent. This requires that care be taken at a number of stages in the research project: at the stage where the investigator is attempting to identify participants who will be suitable for the research; during the conduct of the research on the participants; and during the period that the data obtained are studied, analyzed and reported.

Where subjects consent to participate in research, access to personally identifying information and its use should be carefully guarded. Identifiable data should be coded at the earliest possible time. A minimum number of research staff, all of whom must be instructed about confidentiality requirements, should have access to the data. Where, in the conduct of research, it is necessary to consult a subject’s personal records e.g., school transcripts or health records, this information should be included in the consent process.

In **qualitative research**, direct quotations of participants are typically used in the presentation of results. In this case, care must be taken by the researcher to ensure that the direct quotations used do not contain information that may be potentially identifiable. Participants should also be informed that direct quotations will be used, without identifying information.

**Data Management and Secure Storage**

Data once obtained should be kept secure from theft, copying, interception and/or casual release. Records should be kept in locked cabinets to which access is restricted to as few members of the research team as is reasonably possible. Similarly, data, which are stored on computerized databases, should be rendered secure from access by other users of the system.

At a minimum electronic data must be password protected and preferably encrypted to preserve security of the data. Participant data (without identifying information) and coding lists (with identifying information) should be stored separately.

**Limits on protecting confidentiality**

If there are limits on being able to protect participants’ confidentiality, this should be made clear in the consent process.

Where participants are offered the protection of confidentiality, care should be taken to inform subjects that, while the researcher will not breach confidentiality, research records may well be subject to subpoena, to disclosure by operation of law, and in some cases, to the sponsoring agency, including for monitoring purposes, and where applicable Health Canada, and the Food and Drug Administration in the USA.

If a **focus group** is being used as a method of data collection, full confidentiality cannot be guaranteed on behalf of the other focus group participants. The consent form should clearly note this limitation on the protection of confidentiality. The following is sample wording for a consent form: “While the researcher will maintain confidentiality, we cannot promise this on behalf of other participants, although it will be requested”.

Other limitations on confidentiality include **mandatory reporting**. There is a societal obligation to report child abuse, neglect or suspicion of such to the proper authorities. Many researchers are also clinicians and professionals who are required, by law, to report imminent harm to self or others, and other kinds of serious situations.

If you feel that your research data collection methods may well solicit information about potential harm or abuse or other situations that require reporting, then potential participants should be informed about this possibility/obligation in the consent process.