

C. ETHICAL GUIDELINES

A general formulation of Ethical Considerations to be taken into account in all activities in which human subjects are involved.

While these guidelines emphasise the ethical considerations that are essential when using human subjects, it is expected that all research will adhere to acceptable standards of research practice.

NOTE: These **GUIDELINES** are wholly consonant with the principles laid out in the **Research Code of the HSRC**.

ETHICAL GUIDELINES

1. INFORMATION TO SUBJECTS

- 1.1 University researchers using human subjects will identify themselves to their subjects. They will identify their association with the University, and their status as staff member, student or research assistant.
- 1.2 All subjects will receive the following information necessary to facilitate their giving fully informed consent:
 - a) the nature of the research, its purpose and usefulness;
 - b) a precise description of the procedures in which the subject will be asked to participate;
 - c) the anticipated personal risks, including direct physical, psychological or social harm;
 - d) the methods for protection of confidentiality and anonymity which will be observed by the project supervisor and colleagues in respect of the subject's participation as well as the legal limitations to anonymity and confidentiality (see 6.5);
 - e) the fact that the subject is free to withdraw from the project at any time, even after giving consent and after the project commences.
- 1.3 Where appropriate the subject should also be provided information on:
 - a) the anticipated personal benefits derived from this participation;

- b) what social benefits are anticipated, and to whom they accrue;
 - c) the anticipated risks to a larger social group or a third party;
 - d) the extent to which risks in the project have been pretested, and whether the project the subject will participate in differs from pre-tested practice;
 - e) the possibility that the data from this research project may be stored and used for a different purpose in future without obtaining a new consent from the subject, if this is the case;
 - f) whether the results of the project will be available from the project supervisor when they are published;
 - g) the fact that further information is available from the project supervisor;
 - h) the name of the H.O.D. to whom comments on the project may be directed.
- 1.4 Where the subject is a child or a person under legal disability, full information must be provided to the legal guardian or curator. The project supervisor must also demonstrate that the subject concerned will receive a simple explanation of the elements set out in 1.2a), 1.2b), 1.2e), at a minimum (See also 3. Informed Consent).
- 1.5 Except where the project supervisor justifies an alternative method, the information set out in 1.2 and 1.3 will be presented to the subject in writing, as part of the consent form.
- 1.6 Where the project supervisor justifies presenting the information set out in 1.2 and 1.3 to the subject verbally, the person who presents the information will refer to a printed copy of the information.

2. DECEPTION OF SUBJECTS

- 2.1 Where it is necessary to withhold or to misrepresent significant facts in informing the subject, such deception must be expressly justified in the project supervisor's protocol. In particular, the protocol must demonstrate:
- a) that the deception is indispensable to the effectiveness of the project.
 - b) that the deception must extend to all the elements as proposed;
 - c) that all alternative investigative methods are unsatisfactory;

- d) that the deception will not invalidate the informed consent of the subject;
 - e) that the subject will be fully informed of all elements of the programme which were withheld or misrepresented, by a member of the research project in person, as soon as possible after participation in the project has been completed.
- 2.2 No protocol will be approved where deception disguises or misinforms the subject of the risks, or in itself creates a substantial risk to the subject's self-esteem and dignity.

3. INFORMED CONSENT OF SUBJECTS

- 3.1 A person must give express consent to participate in any University research project or class project as a human subject, free of coercion, constraint or inducement, with information adequate to evaluate the anticipated risks and benefits inherent in personal participation in the project.

Persons are under a legal disability where they cannot be legally bound by their own actions, as with a person under 21 years of age, or a person of limited mental capacity because of senility or disorder. In cases where the subject is under a legal disability, consent must be obtained from the legal guardian or custodian, except where the Human Subjects Committee, in its discretion, allows otherwise (See 1.5 p5). In addition, consent of the subject in person will be obtained except where the subject is incapable of making a decision to give or withhold consent.

- 3.2 Unless the project supervisor has justified the use of verbal consent in the protocol, consent shall be given in writing.
- 3.3 It is preferable that the information and consent forms be integrated; where this is not possible, the following elements of information must appear on the consent form:
- a) the name of the University and name of the project supervisor;
 - b) a brief but explicit description of the procedures the subject personally will participate in;
 - c) an explanation that the subject is free to withdraw from the project at any time, even after having given consent and the project has commenced;
 - d) when a foreseeable risk exists, the consent form shall include an acknowledgement by the subject of the risk involved in the research and a waiver by the subject of any claims arising from the research.

- 3.4 It is recommended that the consent form contain general words indicating that subjects understand that the nature of the variables being considered may make it impossible to be informed completely of the nature and purpose of the procedures to be followed, but that they will be fully informed when their participation has been completed.
- 3.5 Remuneration for participation as a subject in a University research project or a class project, if any, will be based on the time required of the subject and the inconvenience caused, and will not be sufficient to induce the subject to disregard any risks inherent in participation.
- 3.6 Where the subject group is a "captive population", such as populations of correctional institutions and hospitals, provision may be required in the protocol for receiving the consents of the institutional authority and the individual subjects and/or their legal guardians or curators. In respect of this guideline school children and students enrolled in a particular course may be considered as "captive populations".
- 3.7 Provision of informed consent is understood to include consent to publish findings subject to the requirements in respect of subject confidentiality and anonymity.

4. RISKS AND BENEFITS TO SUBJECTS

- 4.1 It is the responsibility of the project supervisor to demonstrate in the protocol, where appropriate:
- a) that a careful analysis of the direct and indirect risks to human subjects of the proposed research project, however remote, has been made, particularly where the subject population displays vulnerability by reason of factors such as age or mental capacity;
 - b) that consideration has been given to the risk of damage or offence to third parties who may identify with subject individuals and groups for racial, cultural or sexual reasons, and to public sensitivity at large;
 - c) that whenever the methodology proposed creates foreseeable risk, the project supervisor or the person authorized by the research supervisor to carry out the project has had previous experience with application of the methodology.
- 4.2 The Committee reviewing the protocol has the duty to decide:
- a) whether the project supervisor has explored the risk factor sufficiently in the protocol;

- b) whether the benefits to the subject personally and the importance of the knowledge to be gained outweigh the risks inherent in the project;
 - c) whether risks have been minimized and provision made to remedy any harm;
 - d) whether the consent the subject will give will encompass all foreseeable risk factors.
- 4.3 Procedures involving physiological intrusions of clear medical concern will be performed by a medically authorized person.
- 4.4 No methodology will be approved whose object is long-term behavioural change to the subject, unless such change is directly beneficial to that subject.
- 4.5 The Committee reviewing the protocol will observe caution in approving any methodology which stimulates negative behaviour, such as anger, aggression, and racial antagonism.

5. PRIVACY OF SUBJECTS

- 5.1 The University recognizes and supports the freedom of persons and communities to reveal or withhold all information about themselves not already in the public domain, by deliberate, fully informed decision, and with the assurance that the subject's anonymity will be protected and all records of participation in a University research project or class project will be kept confidential. Such assurance is subject to the constraints of law (See 6.5).
- 5.2 The project supervisor in his protocol must account for differing sensibilities among subject groups in the matter of invasion of privacy especially if the subject group is a particularly vulnerable one, or of a background radically different from that of the researcher.
- 5.3 The Committee reviewing the protocol will closely examine the proposed use of institutional records in a project. The Committee will consider the potential invasion of the privacy of the individuals whose records are to be used, and the advisability of obtaining consent from those individuals as well as from the institutional authorities.
- 5.4 Consideration must be taken of the privacy of third parties where the subject be asked to disclose information or opinions about such third parties.
- 5.5 Mechanical methods of observation, such as TV cameras, microphones, tape recorders, and one-way mirrors, may be used only with the consent of subjects and/or their legal guardians. Where the subject has been recorded, the subject

must be given the opportunity to call for erasure of the recording when such participation is complete. Any disclosure of a mechanical recording to persons who are not involved in carrying out the project (for instance, as an audio-visual demonstration) must be expressly consented to by the subject.

- 5.6 Use of student records will be consistent with the Universities' policy on privacy of Student Records.
- 5.7 Location of a University research project or class project on private property must be disclosed in the protocol and approved in advance by the property owner. Shopping centres and commercial businesses are private property.
- 5.8 A university researcher who is given access to a government or community institution or agency has a responsibility not to make public exposure of conditions or practices with which the researcher disagrees without first reporting them to the responsible authority and giving reasonable time for an investigation to be made and a decision reached.

6. ANONYMITY OF SUBJECTS AND CONFIDENTIALITY OF DATA

- 6.1 The subject's anonymity will be strictly protected and all data collected will remain absolutely confidential. Where the subject has given written consent, information may be disclosed only within the strict limits of the terms of the consent.
- 6.2 The responsibility is on the project supervisor to describe positive measures to be taken to preserve the anonymity of the research subject, both in the published results of the project, and in the records retained by the project supervisor.
- 6.3 Where confidential data will be stored for possible re-use, the method of recording and storing the data must be strictly designed to confer anonymity on the subject.
- 6.4 All research assistants and persons having access to confidential data must be briefed by the project supervisor on the duty to observe the rules of anonymity and confidentiality set by the Ethical Standards Committee.
- 6.5 In certain circumstances a researcher may acquire information on illegal activities or information relevant to a criminal investigation. A researcher who acquires information about illegal activities may be called as a witness in court proceedings and can be compelled to make full disclosure of such information received. It is recommended that the project supervisor appraise all co-researchers associated with the project of the legal implications in this connection.

7. THE RESEARCHER - CLIENT/SPONSOR RELATIONSHIP.

It is recognised that researchers have the right to receive an explicit research mandate from the sponsor/client. However, the following applies.

- 7.1 Interference by sponsors or clients that may jeopardize the scientific integrity of the study, or prejudice the interests, health or dignity of the subjects is not acceptable.
- 7.2 Information that may reveal the identity of the human subjects may not be supplied to the sponsors/client unless this was included in the original proposal and was part of the informed consent given by the subjects.

UNRESOLVED ISSUES

1. The Ethical Standards Committee recognises that in the foregoing guidelines some wider and indirect consequences of research, particularly in the human and social sciences, may be too narrowly addressed. Some of these effects, for communities studied, may have far-reaching ethical implications, if a researcher finds, for example, that a certain aid programme is not functioning, and may be cut off, with unintended consequences for the people involved. The Committee notes the advisability of formulating guidelines on this matter.