

Participatory Action Research

A. For a project for which there are no prospects of publication of the results of the research to anyone other than the group involved in conducting it, EITHER because the project is a class exercise OR because it is being conducted for a group whose interest in the findings is wholly internal, THEN there is no need to seek IRB approval for the project at all.

1. However, a listing of such projects (a) should be maintained by the UT unit and (b) should be made available for review by the IRB or its representatives upon request.
2. If confidentiality is **not** to be maintained (either with regard to the identities of subjects or with regard to information that has been gathered about them), this should be made explicit. If it **is** to be maintained, participants should be provided with (a) a list of those who will know subject identities and (b) a description of protection measures that will be employed to prevent confidential information from becoming generally known.
3. All those involved in conducting the project should be informed at the outset that a more formal approval by the IRB AND a more formal consent by the participants will be required if a decision is made later to publish project results.

B. For a project classifiable as "contract research" -- i.e., for which the role of the UT unit is limited to carrying out a project on behalf of a local group, which was designed and will be interpreted by the group itself, a short-form application will be submitted to the IRB which outlines the limited role of the UT unit and describes the nature of the cooperating group.

1. The project information sheet/informed consent form which is given to prospective subjects (a) should NOT contain any statement indicating that the project has been approved by The University of Tennessee IRB and (b) should indicate with some precision the limited role of the UT unit in designing, conducting, and/or interpreting this project.
2. Confidentiality provisions similar to those specified in A.2 should be distributed to all those asked to serve as subjects of the research.
3. Future-consent provisions (*cf.* A.3) should be communicated to all involved.

C. For a project for which the UT unit serves a co-equal role with the community group in designing, conducting, and interpreting the research project, EITHER (a) both groups should be listed on information sheets and/or consent forms -- as well as on a Form A or Form B (as appropriate) submitted to the UT IRB OR (b) the community partner should have completed an agreement to abide by the fundamental principles of research ethics. (See Appendix below for this list.)

1. Confidentiality provisions outlined in A.2 apply.
2. Plans for publication (if any) should be included in the consent form.

D. For a project for which the UT unit is the PREDOMINANT party (e.g., in which the community partner's role is limited to suggesting the research questions and receiving the interpreted results), the UT faculty who is carrying out the project will be listed as Project Director and the standard approval process like that for traditional research will be undertaken, using Form A or Form B, as appropriate.

IN ADDITION, we recommend that the community representation on the UT IRB be expanded to include at least one representative of the segment of the community that would be involved in projects of this type.

Submitted by the UT IRB Subcommittee on Participatory Research: Chaired by Glenn Graber

NOTE: These proposals are framed in terms of the following typology of research elements:

Community participants may have an active role in the research in one or more of the following ways:

- **DEFINING** the questions to be answered by the research;
- **DESIGNING** the research method to explore the questions;
- **CONDUCTING** the research project -- i.e., choosing subjects, administering questionnaires, etc.;
- **ANALYZING** the data;
- **INTERPRETING** the results -- i.e., evaluating the significance of the data and drawing conclusions about the answers to the initial questions posed; and
- **DISSEMINATING** the results through publication, etc.

(We are indebted to John Gaventa for this helpful listing of the constituent aspects of a research project.)

APPENDIX:

"Plain English" Principles of Research Ethics

We here acknowledge our acceptance of the following research ethics standards as guiding principles of our activity in partnership with a unit of The University of Tennessee:

A. We will demonstrate our respect for all the people we encounter in the course of this research project by:

1. Informing them fully of what we are doing;
2. Answering any questions they may have about the project;
3. Asking their consent before involving them in any way;
4. Reminding them that they are free to refuse to participate; and
5. If someone is not fully capable of understanding what we are asking them to do (young children, for example), we will either not enlist them or we will seek consent from someone authorized to serve as their guardian or surrogate.

B. We will demonstrate our concern for the welfare of all the people we encounter by:

1. Designing our project in a way that avoids harming them in any way – including, not only physical harm and emotional turmoil, but also embarrassment that might result from private information about them being made public;
2. Monitoring how the project affects those involved throughout and inviting them to withdraw from participation if harm results;
3. If significant harm does result, (a) instructing the participants affected to withdraw, (b) helping them deal with the harm (*e.g. by obtaining medical help or counseling services*), and (c) informing the UT coordinators of the project immediately so they can report it to the appropriate authorities; and
4. At the end of the project, we will help participants deal with any confusion, misunderstanding, or harm of any sort that might remain as a result of their participation.

C. We will demonstrate our concern for justice by:

1. Designing the project and choosing participants in such a way that no person or group of persons is unduly burdened or placed at risk.

D. We will demonstrate our respect for the enterprise of scientific research by:

1. Recording all research information accurately;

2. Interpreting it fair-mindedly;

3. Reporting it honestly; and

4. Honoring the requests of the UT coordinators for oversight of the process and allowing them to discuss it with UT research compliance authorities as required.

BACKGROUND PRINCIPLES:

A. RESPONSIBILITY OF PROJECT DIRECTOR

By the compliance with the policies established by The University of Tennessee, Committee on Research Participation, the project director subscribes to the principles stated in The Belmont Report and standards of professional ethics in all research, development, and related activities involving human subjects under the auspices of The University of Tennessee.

1. Approval will be obtained from the University Committee prior to instituting any change in the research project.

2. Development of any unexpected risks will be reported to the University Committee.

3. A status report (Form D) will be submitted at 12-month intervals or as requested attesting to the current status of the project.

4. Signed consent statements will be kept for the duration of the project and for at least three years thereafter.

BASIC ETHICAL PRINCIPLES*:

Respect for Persons -- Respect for persons incorporates at least two ethical convictions:

1. That individuals should be treated as autonomous agents; and
2. That persons with diminished autonomy are entitled to protection.

An autonomous person is an individual capable of deliberation about personal goals and of acting under the direction of such deliberation. To respect autonomy is to give weight to autonomous persons' considered opinions and choices while refraining from obstructing their actions unless they are clearly detrimental to others.

Respect for the immature and the incapacitated may require protecting them as they mature or while they are incapacitated.

Beneficence -- Persons are treated in an ethical manner not only by respecting their decisions and protecting them from harm, but also by efforts to secure their well-being. Such treatment falls under the principle of beneficence. The term "beneficence" is often understood to cover acts of kindness or charity that go beyond strict obligation. In this document, beneficence is understood in a stronger sense, as an obligation. Two general rules have been formulated as complementary expressions of beneficent actions in this sense:

1. Do not harm; and
2. Maximize possible benefits and minimize possible harms.

Justice -- An injustice occurs when some benefit to which a person is entitled is denied without good reason or when some burden is imposed unduly.

There are several widely accepted formulations of just ways to distribute burdens and benefits. Each formulation mentions some relevant property on the basis of which burdens and benefits should be distributed. These formulations are:

1. To each person an equal share;
2. To each person according to individual need;
3. To each person according to individual effort;
4. To each person according to societal contribution; and
5. To each person according to merit.

*National Commission for the Protection of Human Subjects of Biomedical and Behavioral Research, Belmont Report - Ethical Principles and Guidelines for the Protection of Human Subjects of Research. **44 FEDERAL REGISTER** 76 (Wednesday, April 18, 1979), pp. 23192-23197.