

## **Annex H**

### **ETHICS GUIDELINES - RESEARCH WITH HUMAN SUBJECTS**

While recognizing the vital importance of research to human progress, the Council affirms that the welfare and integrity of the individual or particular collective must prevail over the advancement of knowledge and the researcher's use of human subjects for that purpose. The Council is not itself vested with any authority to decide when an individual's rights may be superseded by the need for research but, as a trustee of public funds, the Council has a responsibility to ensure that the activities it supports respect the rights of the public it serves.

The guidelines are offered to assist the researcher and the institutional ethics review committee in avoiding any adverse effects of research involving human subjects.

#### **Institutional Ethics Review Committees**

1. Research projects involving human subjects must be approved by the ethics review

## **Rights of the Individual**

8. Certain individual or collective "rights" must be maintained. These include: the right to know the precise nature and purpose of the research, so that consent may be given or withheld advisedly; the right to know of the risks and benefits; the right to assurance that privacy will not be invaded and that information disclosed will remain confidential; the right of cultural groups to accurate and respectful description of their heritage and customs and to the discreet use of information on their lives and aspirations.

## **Informed Consent**

Information given to subjects should respect their levels of comprehension. A description should be provided of purpose; usefulness; expected benefits; methods; effects; risks (including risks to physical and psychological well-being and jeopardy to social position) and possible alternative procedures. Subjects should always be told of factors which might lead them to refuse to participate. In exceptional circumstances, the guidelines on deception should be applied.

9. Participants should be apprised of the rights to inquire about the research and have recourse to a resource person outside the research group.
10. There should be no coercion, constraint or undue inducement (see special guidelines for captive and dependent populations).
11. Participants should understand that they may withdraw at any time, just as investigators may terminate their research in the interest of the subjects, the project or themselves.
12. Informed consent of parents or guardian and, where practical, of children should be obtained in research involving children (see special guidelines concerning research on children).
13. Participants should be informed of the degree of confidentiality that will be maintained in the study.
14. Informed consent should be obtained in writing. Where this is not practical, the procedures used in obtaining consent should be on record.
15. Written consent should set out:
  - a) purpose of the research;
  - b) benefits envisaged;
  - c) any inconveniences;
  - d) tasks to be performed;
  - e) rights of the subject, e.g. the right to withdraw at any time without penalty the right to confidentiality of personal information;



domain. It gives to the individual or collective the freedom to decide when, where, in what circumstances and to what extent their personal attitudes, opinions, habits, eccentricities, doubts and fears are to be published.

24. If there is to be a probing of private personality or private affairs the intention should be explicit. Where there is an implication of protection of privacy, the protection should be more generous than the promise.
25. Informed consent should be obtained from those to be observed or studied in private settings.
26. Since concepts of privacy vary from culture to culture, the question of invasion of privacy should be looked at from the point of view of those being studied.

### **Confidentiality and Anonymity**

27. If confidentiality or anonymity cannot be guaranteed, participants should be made aware of possible consequences.
28. There should be a clear understanding between investigator and subjects as to what extent information they divulge will be kept confidential in the original use of data and their deposit for future use.
29. Unless there is an explicit statement by the researcher to the contrary, to which the subject agrees, personal information given by the subject will be confidential and the researcher will explain steps to be taken to ensure confidentiality and anonymity.
30. Steps should be taken to guard against indirect or unwitting disclosure of identity of subjects by association or by combination of information.
31. The researcher has an obligation to third parties.
32. Obtaining access to institutional record should respect the individual's rights to confidentiality and anonymity.

## **Research on Children**

36. Informed consent of parents or guardians should be obtained before using minors. In school, camp, or other group settings, consent of the principal, director or other appropriate authority must also be obtained. Where a child is a ward of the state or of an agency, such as the Children's Aid Society, informed consent of the agency director, as well as of the person having custody, must be obtained.
37. Children should be given individually the opportunity to refuse to participate or to withdraw.

## **Research in the Humanities**

38. Research ethics are involved wherever an investigator intervenes in the lives of others. Historical and/or biographical investigation may pose problems of confidentiality or invasion of privacy if living persons are likely to be affected by the publication of private materials.
39. Researchers should be careful, in purchasing and taking out of the country original manuscripts, that they are not depriving another country of what may be a national treasure.
40. Those writing history, biography or artistic criticism should be aware that private papers, photographs or artistic productions are protected by copyright, regardless of whether such material resides in an archive, gallery or museum. One cannot legally consult, cite, reproduce, publish, refer to or distribute such documents or articles without permission, either from the author or heirs or from the person or institution given copyright ownership.

## **Acquisition and Use of Cultural Properties**

41. Acquisitions should be for the purpose of scholarship and not for personal gain, private collection or sale.
42. Legal requirements of the country of origin must be observed.
43. Where there is doubt as to legal ownership, the researcher acquires an object at risk and must immediately inform the authorities of the country concerned. If the acquisition is not approved, the researcher should return the object to those authorities.
44. The researcher should not accept or otherwise acquire objects unless proper storage, protection and preservation of the objects can be provided.
45. Materials should be catalogued, with a description of their provenance, Op T89(thot ) TE3 71(a)4(t).

48. All copies or reproductions of documents and objects, whether collected for exhibition or distribution, should be clearly marked.
49. Material should not be publicly exhibited, discussed or published in a way which causes embarrassment to individuals, groups or countries associated with it.
50. Objects or documents should not be exhibited in ways likely to damage them.

### **Research on Other Cultures, Countries and Ethnic Groups**

Research on cultures, countries and ethnic groups different from one's own requires a