The Aga Khan University

GUIDELINES

GUIDELINES ON RESEARCH ETHICS FOR SOCIAL SCIENCES, HUMANITIES AND ARTS (SSHA)	
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A. PREAMBLE

The following are key principles on which project ethics are evaluated: informed voluntary consent; privacy, confidentiality, anonymity; reciprocity; and no/ minimal harm assessment.

Failure to obtain consent from a participant is an ethical issue which could have legal consequences for the researcher as well as the University. Lack of consent, or an ineffective consent, could result in civil actions for assault, negligence or breach and confidentiality.

The ERC will examine project documents that might involve deception of the participant. While informed consent does not imply that the participant must have complete foreknowledge of everything that is to happen in the project – researchers must take steps to minimize the extent of any deception or possibility the participant has given a partially informed consent.

B. GUIDELINES

1. Informed Consent

1.1. If personal data is gathered, legally and ethically consent must meet three criteria: 1) it must be voluntarily given; 2) it must be informed; and 3) the person must have capacity to consent.

1.2. A voluntary consent means consent is freely given which in turn requires the participant to be under no coercion or compulsion to give consent. Consent should not be in return for monetary benefits to the participant. However, in cases when participants are required to travel to participate in, for example, an interview or focus group interview, reimbursement for time and travel may/should be provided to the participant which should commensurate with the time spent.

1.3. A participant has capacity to give consent when he/ she understands what is being requested. The law presumes an adult of sound mind has capacity to give consent, but researchers need to consider special characteristics possessed by the participant when seeking consent.

1.4. In most cases a person over age 18[1] is deemed to capable of consent. Before age 18, the parent or guardian/ principal can give consent on behalf of the minor. The ERC expects parents/or legal guardians of children of this age be informed even if not being asked to consent.

1.5. In the case of participants whose age and mental capability may limit their understanding and agreeing to voluntarily participate in the project, the researcher should seek alternatives in which these participants are enable to formulate a reliable response or consent. For example, they can seek the collaboration and approval of the parent/legal guardian responsible for the participant (s) or h/her legal guardian.

1.6. Cultural appropriacy and sensitivity will be considered when seeking an informed consent from research participants. For example, in the case of seeking an informed consent from women in the Pakistan for community-based studies some negotiation and communication with male members of the family might be considered appropriate and necessary but it will not replace the need to confirm that the woman is informed, has capacity and in voluntarily giving an informed consent.

1.7. For community studies, community leaders, elders, local political leaders or other key stakeholders should be taken into confidence and written consent must be obtained from them. If these individuals participate in the project then informed consent shall be received from them.

1.8. The consent form shall be printed on AKU letterhead in accordance with AKU policy.

[1] https://www.unicef.org/crc/files/Guiding_Principles.pdf

1.9. Researchers must ensure that the idea of informed consent is clearly comprehended by participants. The language must not be technical. The consent form should be developed in simple words, preferably in the local language. It must give as much information as required to allow an informed decision to be made.

1.10. An informed consent of a participant should be obtained at a reasonable time prior to or at initiation of the project.

1.11. The researcher must indicate the purpose and procedure of the project that the participants are expected to undergo (e.g. sources of information - interviews, observations); duration of research, frequency of meetings with participants (e.g. number of interviews/observation); expected duration of meetings (e.g. interview will take 40-50 minutes; observation of a complete session); as well as [possible risks and benefits to participants].

1.12. The Consent form must inform the participants of their right to withdraw for any or no reason, and at any time, and without penalty. The researcher should recognize and respect this right of participant.

1.13. Data collection tools such as a survey, questionnaires, interview guide, and observation protocol must be included in ERC applications. In studies of an on-going or exploratory nature (e.g. anthropological fieldwork) it may be possible to include only the first instrument to be used. A project is subject to the standards set out in the appropriate Code of Practice of respective fields. If the expected outcome of the project is development and validation of a tool (e.g. survey the NTD, questionnaire) ERC would not expect the final tool to be submitted with an application.

1.14. A signed copy of the consent form should be provided to the participant. Moreover, research participants must be advised where to direct that complaints or concerns about conduct of the project (e.g. if in the case of faculty principal investigator, student, supervisor). Participant must be told, preferably in writing, who they should contact for answers to related questions about the project and their rights, and whom to contact in the event of a project-related injury to the participant.

1.15. If the project evolves over a period of time (e.g. longitudinal study), the researcher must ensure that any new development that may affect a participants' willingness to continue is communicated to them. Researchers should obtain a new consent from the participant that clearly sets out changes in the research protocol or process.

1.16. Exceptions in obtaining a written consent from research participants can be made in the case of telephone surveys, and projects involving mass distribution of

questionnaires as well as in the case of participant who cannot read and/or write. For some questionnaires, return of the questionnaires is reasonably taken as an indication of voluntary consent to participate. If the researcher is approaching consent in this manner, this fact should be stated on the questionnaires itself.

1.17. Name and contact number of the principal investigator/researcher must be provided to the participant should he/she wants further clarification or information about the study. This information should be part of the consent form.

1.18. A number of research methods about humans are not affected by the above **[**if no personal data is gathered.] Example include fieldwork observations of crowds if no films or photos are taken. Images that can lead to people being identified without their expressed consent have to be treated as personal data and as rules and regulations are different in different countries, a strategy regarding how to evaluate images has to be included in the application.

1.19. Personal data that is public (from archives, media as example) can be used without consent.

2. Privacy, Anonymity and Confidentiality

2.1. The consent form should inform participants about the degree of confidentiality or anonymity that will be provided and how this will be maintained by the researcher. The researcher must explain what confidentiality and anonymity means.

2.2. The researcher must consider issues of identification of the participant, privacy, anonymity and confidentiality, access to the data by persons other than the researcher, and publication of the data.

2.3. The research participant should be informed about how and why their personal data is being stored and who has access to this data/information. The degree of confidentiality or anonymity, and how this will be maintained must be emphasized when data involves personal or biographical information about the participant.

2.4. If the participant wishes or agrees to allow their identities to be disclosed, in consultation with other research participants', permission must be given in writing (hard copy) and electronic (soft copy) forms.

3. Reciprocity

3.1. The researcher shall consider a variety of ways through which the participants could be compensated for their time and information (e.g. offer a summary of the research results, acknowledgment, thank you letters; conducting a professional development workshop for teachers/staff in school).

3.2. Potential benefits (to the person, institution or society, including information that there is no direct benefit) must be shared with participants in the consent form.

4. No/Minimal Harm/Risk

4.1. Anticipated risks, harms (physical or psychological) or inconvenience (e.g. specific seating arrangements for administering questionnaire/achievement tests, inappropriate time or venue for interviewing vulnerable participants) must be disclosed to the participant prior to the research commencing. Information must include degree of discomfort they may experience, and major strategies or safeguards in place to protect them from harm.

Note:

Studies which are unlikely to produce any significant results because of faulty design are often considered unethical as such studies cause wastage of time and resources. These should be avoided unless there is a strong justification