

ETHICAL GUIDELINES AND CHECKLIST: ACTION PROJECTS

This contains ethical guidelines for action and action research in health and a checklist to guide an exercise of addressing ethical issues involved.

CEHAT is engaged in both research and action. At the time when the IEC got constituted the 'Ethical Guidelines for Social Science Research in Health' prepared by the National Committee for Ethics in Social Science Research in Health (NCESSRH) provided concrete framework to evolve institutional mechanism for ethical review of research based activities and projects in CEHAT. There was no such framework available that could be used in case of action and action research projects. Those engaged in health action or action research has been grappling on their own to address the ethical dilemma they face during their work. It was therefore felt that the project teams within CEHAT engaged in action or action research deliberate on the ethical issues and dilemmas they faced to lay down the framework or ethical guidelines for action related activities in a limited sense. As a result of this collective effort within CEHAT and subsequent consultation with the IEC members the ethical guidelines for action research in health were laid down. This formed the foundation to prepare a checklist for action researchers to use as a tool to guide their exercise to address ethical issues in a more systematic manner.

There is only one comprehensive checklist, unlike four for four stages in case of research projects. This is because it is difficult to demarcate the phases in the action research projects and because they are of a different nature in different projects. Keeping this in mind, action projects are reviewed for their ethical content at least once a year. Action project teams are welcome to approach IEC in other situations, too.

ETHICAL GUIDELINES FOR ACTION PROJECTS: A PERSPECTIVE NOTE

1. How are action projects different?

It is clear that the ethical review of action projects needs to be somewhat different from that of research projects. To understand this we need to take a closer look at how action projects differ from research projects in their approach. Some special features are:

a. There is a deliberate intervention, interfering in an existing situation with the explicit, primary objective of improving it but the possibility of worsening it. When we are systematically 'meddling' with an existing set-up we would like to be very definitely convinced that there is definite benefit and no harm/minimal harm which would justify such an intervention. But is predicting this always possible?

- b. The question of consent: How can we obtain consent from a heterogeneous community, with various groups, strata, conflicting interests...who may never agree or come together?
- c. The partisan nature of certain interventions. Certain of our interventions may lead to benefit for a specific group (women, tribal, etc), may even benefit a majority, but there is possibility of loss to some that are presently privileged or dominating. How do we balance this?
- d. Disturbing an existing equilibrium may lead to an intermediate stage of 'chaos'. When an intervention is introduced, there is a period when an element of friction and struggle emerges. Old support structures may collapse while new structures are yet to fully evolve. What are the ethical considerations in creating such a situation?
- e. Confidentiality is problematic when we convert 'private' problems into public issues. By their very nature, addressing issues like domestic violence may involve bringing 'private' issues onto the public domain.
- f. Tremendous flexibility of strategies is required while implementing community-based interventions. It is not always possible to predict beforehand what strategies would be adopted at a later stage. How do we address ethical issues emerging from time to time during an open ended process?
- g. The question of personal conduct of a social actor: Each person working on behalf of an external agency is also an individual with personal inclinations and weaknesses. When such an individual commits an apparently unethical act, what is the responsibility of the agency? What if personal and community ethical values differ? Is the agency answerable to the community? Can it punish the individual? How is this balanced with the 'image' of the work and the movement?
- h. The question of partnership: There should generally be a sharing of initiative and responsibility between the external agency (NGO) and the local activists/organisation. This partnership is itself dynamic and generally should lead to more and more responsibility being taken locally. However the nature of this sharing (its evolution over time, its status both when a crisis comes up and when issues of credit arise) is central to the dynamics of the process yet often impossible to define in black and white.
- i. The question of responsibility: When we intervene in a situation and unfortunately certain backlash/undesirable consequences ensue (a woman is thrown out of her husband's house, a seriously ill activist is refused treatment by a vindictive doctor) what is the nature of our responsibility to help as a project team and as an NGO?

j. The question of sustainability of commitment: Most NGOs work on the basis of time bound projects while social action is an endless, ongoing process. The question of withdrawal – when and how – is a tricky one in any intervention process and raises ethical issues of its own kind.

2. What should be the scope and process of the ethical review of action projects?

When the situation is as complex as outlined above, it is apparent that the ethical review also needs to be broader in its scope and perhaps more indicative than prescriptive. It seems difficult to lay down precise guidelines, which would apply in all details and uniformly to all projects and situations. Often the exact dynamics of a decision taken by the action team in a particular situation may be difficult to comprehend for a person who is ‘outside’ the entire situation. Yet there is a value in formulating certain broad ethical guidelines and reviewing the projects adherence to these guidelines on a periodic basis. The following framework could be suitable for ethical review of action projects:

- a. The action team may go through the checklist and respond to the major issues
- b. This should be discussed by the team with the assigned IEC members and any contentious issues sent back for further discussion within the team and modifications by them
- c. Wherever technical issues are involved special consultants are asked to give their opinion
- d. The project is reviewed periodically (every six months or one year) and ongoing modifications are made accordingly.

3. What should be the key issues addressed by the checklist?

a. Benefits and risks:

- i. Perceived benefits of the interventions - major benefits and spin-off effects
- ii. Perceived risks of the interventions - those which are inevitable, those which are avoidable, possible catastrophic situations
- iii. Key technical issues regarding interventions: relevant experts may be consulted for opinions on this
- iv. Identifying any specific groups / individuals which may systematically stand to lose by the intervention
- v. Overall assessment of benefits versus risks

b. The main partners and the consultative process (parallel to ‘consent’ for research)

- i. Identifying the main interventions and the core beneficiary group(s)

- ii. Mechanisms for dialogue and communication with this group and its representatives at various stages (before initiating the process, to review the process, during withdrawal or change in level of intervention)
- iii. Defining the specific responsibilities of various partners and how these are expected to evolve over time.
- iv. In case persons with a particular problem are being catered to, the definition of this problem should be clear and those not covered by this definition should be covered by an appropriate protocol.

c. Local Relationships:

- i. Within the CEHAT team
- ii. Between the CEHAT team and the Community
- iii. Between the CEHAT team and the local collaborating organizations

How to ensure that these relationships are based on transparency, fairness, autonomy and overall mutual beneficence? The responsibility of CEHAT vis-à-vis partners should be defined and adhered to.

Recognition of differences in cultural background of external agency staff and community/beneficiaries. Methods of resolving conflicts related to these various relationships.

Confidentiality regarding details of a particular person interacting with the team may have to be maintained. However, it could be made clear to such persons that information revealed to any team member would be shared *within the team*.

d. Broader relationships:

- i. Between the CEHAT team and the civil society at large as well as the State.
- ii. Between the CEHAT team and the funding agencies.

The developments including shortcomings of the activity should be communicated to society at large honestly and faithfully. Similarly, commitments to funding agencies should be respected and communications made to them. Mechanisms should exist to resolve conflicts between commitment to funding agencies and to the community.

e. Processes for empowerment and sustainability

How would skills, organisation and capability be developed in a phased fashion so as not to create dependence but rather make the external inputs unnecessary over a period of time? The withdrawal strategy, a responsible ensuring of the sustainability of the process and safeguards against backlash or vindictive actions by privileged groups would need to be formulated.

f. Crises and unforeseen situations:

- i. Wherever structures are being disturbed, to ensure that processes to cope with this situation are in place; both in terms of capability building of the community and commitment of the organisation.
- ii. A broad 'contingency plan' should be formulated for crisis situations especially regarding how decision making will be done, how responsibilities will be shared and what would CEHAT's commitment be in this regard.

CHECKLIST FOR ACTION PROJECTS

1. Expected benefits and risks of the intervention process

- a. What are the expected benefits of the interventions?
- b. What are the perceived risks?
- c. What safeguards have been made to maximize the benefits and minimize the risks?
- d. Are there any key technical issues regarding interventions, and if so how are relevant experts going to be consulted on this?
- e. Does the overall assessment of *benefits versus risks* justify the intervention effort?

2. Partners and consultative process

- a. Which are the main partners and what is the consultative process (parallel to 'consent' for research) with these partners?
- b. How will you ensure transparency in the process of ongoing communication with these partners?
- c. What is the planned MOU or other explicit definition of specific responsibilities of CEHAT and various partners?

3. Local relationships

- a. Relationships would exist within the CEHAT team, between the CEHAT team and the people and between the CEHAT team and the local organisations. How would it be ensured that these relationships are based on transparency, fairness, autonomy and overall mutual beneficence?
- b. How would decisions be taken within the team and how would differences be resolved?
- c. How would the confidentiality of persons approaching the team be maintained and how would confidential information be shared within the team?
- d. In case training and service delivery are components of the project, how will it be ensured that persons will deliver services only in keeping with the level of training they have received?

4. Broader relationships

- a. How will developments including shortcomings of the activity be communicated to society at large?
- b. How will it be ensured that commitments to funding agencies are respected? And what mechanism of regular communication with them will be adopted?
- c. By what mechanism will possible conflicts between commitment to funding agencies and to the community be resolved?

5 Processes for empowerment and sustainability

- a. How will skills, organisation and capability be developed in a phased fashion so as to not create dependence but rather make the external inputs unnecessary over a period of time?
- b. What is the withdrawal strategy, attempting a responsible ensuring of the sustainability of the main processes initiated by the project?

6. Crises and unforeseen situations

- a. What is the broad 'contingency plan' for crisis situations especially regarding how decision making will be done, how responsibilities will be shared and what is CEHAT's commitment in this regard?
- b. What are the 'Safety plans' for persons who may face problems because of involvement in project-initiated processes?
- c. What are the mechanisms to ensure the personal safety (while involved in project-related work) of CEHAT staff and other persons directly related to the project activity?