Thelma Narayan

National Meeting to Discuss
The Draft Code of Ethics
For Research in Social Sciences
And Social Science Research in Health

May 29-30, 2000
At the YMCA, Near Maratha Mandir Cinema, Mumbai Central, Mumbai
Organised by CEHAT, Mumbai

TENTATIVE PROGRAMME

May 29, 2000: Monday

09.30-10.00:	Self-introduction of the participants and the theme of the meeting
10.00-10.30:	Presentation: Need and scope of the ethics in social sciences, and pitfalls to guard against while codifying ethics
10.30-11.00:	**Tea/Coffee break**
11.00-12.00:	Discussion.
12.00-12.30:	Presentation: Sections I (Preamble), II (Principles) and III (Guidelines) of the proposed code.
12.30-13.00:	Clarifications
13.00-14.00:	**Lunch**
14.00-17.30:	Group Discussion (All Groups Will Discuss Sections I to III) Participants will divide into three Groups A, B and C, each with a Facilitator and a Rapporteur.

May 30, 2000

09.30-10.15:	Presentation of consolidated report of three groups by one representative of the three rapporteurs.
10.15-10.30:	Clarifications and discussion
10.30-11.00:	**Tea**
11.00-11.15:	Presentation: Section IV of the proposed code on the implementation mechanism.
11.15-13.00:	Group Discussion (All Groups Will Discuss Section IV) Participants will divide into three Groups A, B and C, each with a F acilitator and a Rapporteur.
13.00-14.00:	**Lunch**
14.00-14.30:	Presentation of consolidated report of three groups by one representative of the three rapporteurs.
14.30-15.30:	Clarification and Discussion
15.30-16.00:	Concluding remarks, Tea and Dispersal

NOTE ON THE PROGRAMME

The programme given above is tentative, so it might undergo some change. In case you have any suggestion, please do let us know the latest by May 25. The meeting will end the latest by 4 (four) in the afternoon on May 30, 2000. For those who have requested accommodation are booked at the YMCA International House.

Feedback

We made active efforts to collect feedback on the proposed draft code from researchers and institutions across the country. The process followed by us and the comments received are summarised in a feedback paper. Some of the presentation would cover the feedback, and the participants are requested to address to the issues raised therein.

Session plan

The feedback contributed substantially in planning the discussion sessions of the programme. Accordingly, the discussion would cover the following three major areas:

(a) **The Need and Scope of the Ethical Code, and Pitfalls in Codifying Ethics in Social Science Research:** Many researchers have genuine concerns, and we must collectively address to them. This process is intended for the good of social sciences and research, and so we must collectively endeavour to convert good intentions into appropriate code and its implementation mechanism.

(b) **The Body of the Code:** Sections I (Preamble), II (Principles) and III (Guidelines), collectively constitute the body of the code. Each formulation needs to be examined in detail by the community of researchers. We have therefore allotted maximum time for discussion on this aspect.

(c) **The Implementation Mechanism:** From the feedback received so far it seems that this issue would need detailed discussion and resolution of some of the dilemmas. Indeed, it will have direct connection to the issues of scope and pitfalls discussed in the first session.

Background Papers

We commissioned seven background papers for the meeting. They document some of the issues and experiences in various fields, and some of them also elaborate the points covered in the draft codes. We hope that participants would find them of use for examining and analysing the guidelines.

Since the background papers are not commissioned for discussing the specific views of the author, **they will NOT be presented**. However, during the group discussions the authors will be available to the participants as resource persons.

Some Relevant Code of Ethics

Although we have collected several codes of ethics (over 1000 pages) of different disciplines and countries, it is not possible to provide a copy to all participants. Of course we would keep a copy of all at the meeting for your ready reference.

In this collection we have given two sociological codes and one code on collaborative research for your information.

Outcome

We know that adoption of a consensus code by the vast, dispersed and diverse social science research community in India, is a process. The CEHAT and the drafting committee are strongly committed to the gradual evolution of the most suitable code of ethics for social sciences, its voluntary acceptance by the social science community and its democratic implementation in a decentralised manner.

The CEHAT will be publishing the proceedings of the meeting and the code revised by the committee based on the discussion we all will have at the meeting.

Summary of Feedback Received on The Proposed Draft Code of Ethics

Prepared by
The Secretariat of the Drafting Committee

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The Draft Code of Ethics

For Research in Social Sciences And Social Science Research in Health

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YMCA, Mumbai Central
Mumbai

Organised by

CEHAT
(Research Centre of Anusandhan Trust)
2nd Floor, BMC Bldg., 135 Military Road
Next to Lok Darshan, Marol, Andheri East
Mumbai 400 059. India
Tel: (91)(22) 851 9420, Fax: (91)(22) 850 5255
Email: cehat@vsnl.com

Summary of Feedback

Background:

The research for the drafting of the code was very daunting. We collected nearly thousand pages of similar social sciences, psychology, medical and other research codes from different parts of the world, and more material still keeps coming. Ten members of the drafting committee and two members of the research secretariat at the CEHAT met twice to discuss the drafts of the guidelines. The research secretariat was in contact with the members of the committee between the meetings. The second meeting of the committee examined each line of the draft and made numerous general and specific suggestions for modification and redrafting of the code. This meeting also decided that all possible efforts would be made to invite feedback and suggestions from the social science research community - individuals as well as institutions. Accordingly, in addition to those invited for the May 29-30 meeting, many more were sent the draft. Besides, as per the recommendation of the committee efforts were also made to organise meetings for the presentation of the draft to researchers, teachers, and students in six institutions (three from Mumbai, and three from outside) and one person from the research secretariat had direct interaction with them.

Above all, since the recommendations made by the second meeting of the committee demanded very rigorous effort in redrafting, the committee had recognised that there would not be adequate time for the members to reflect on and respond to the new draft. The secretariat was thus instructed to circulate the proposed draft for discussion without discussion within the committee. So this paper also contains feedback from some of the committee members. Indeed, this situation also brings all participants on the equal plane for discussing and learning about the researchers ethical responsibilities and rights, and for making suggestions for appropriate modifications in the draft code. Needless to add, the members of the committee would take all suggestions into consideration before finalising the code within two months after the meeting.

21 out of 100 odd individuals who were sent the draft, responded. Of them, six did not offer any substantial comments except for commending the efforts being made. *So this paper summarises responses from 15 individuals hailing from institutions (including NGOs) across the country.* The meetings organised at the six institutes were fairly well attended. **Over 80 teachers, researchers and students** listened to the detailed presentation of the draft made by one researcher of the secretariat and participated in the discussion that followed. Most of the meetings lasted for more than two hours. In each meeting one person took detailed notes of the discussion. *This paper also contains summary of comments received in these meetings.*

Although it was not possible to cover every thing, we have tried to summarise and classify as many comments as possible without making too many changes in the way they were conveyed to us. However, you would bear with us in case inadvertently we have missed out or misrepresented any comment. (The emphasis in *italic,* through out this paper, are added.)

Please note that each paragraph is a separate comment received on the draft of the code and the wording of each comment has been edited. Therefore, under each section and sub-section there may be totally opposite and conflicting paragraphs of comments. Such cases only show the differences existing among those who responded.

SUGGESTIONS FOR MAKING ADDITIONS

Add glossary and explain terms such as non-maleficence, beneficence, autonomy, justice, risk, non-exploitation, and so on.

Formulate and add guidelines on the *relationship between researchers and their organizations*. They should also cover the complexities involved and the issues related to ownership of data. Same way, we need guidelines for the *relationship between institutions*. What happens when there is conflict between collaborating institutions? Who own the data, or how do they share them?

Formulate and add guidelines on *collaborative and action research.*

Guidelines on the responsibility and accountability of the *junior members* of the research team and *students* may be added.

The guidelines should also address *the ethical issues involved in advocacy*, using results of the research in social sciences and health.

The guidelines should provide for *sanctions/punishment for their violation*. There is also a need to formulate procedure for the probe into allegations of violation or approaches that need to be taken if the code is violated.

GENERAL COMMENTS

Timing:

It is *too early* to formalise and finalise the guidelines. We should wait for more time.

Social science different from other sciences:

What is the demarcation between medical research and health research? Do we mean to include clinical research in health research? This part needs clarification.

The document suffers from two deficiencies. At one level it is too general, and yet at another level it seems to be influenced by the experiences in health research.

The idea of a discussion on the question of ethics in social science research is necessary. However, before one draws; guidelines for social science research it is important to understand the nature of social science and *distinction between social sciences and other sciences, like physical sciences, medicine and even health*. The fact that social sciences deal specifically with human beings as subjects imparts certain uniqueness to this field. There is *qualitative dimension*, which cannot be ignored. While medical and health research also deals with human beings as subjects, there is a distinct difference since it is easier to draft guidelines and codes of conduct in medical and health research. *What imparts uniqueness to the social sciences is that it is not value free and ideology plays an important role.* It would seem that this distinction has not got sufficient attention in this document.

The same principles cannot be applied to social science research and health research. It is difficult to formulate detailed guidelines in social science research, and much has to be left to the specific perspective and orientation of the researcher and the nature of the particular piece of research. But this does not, of course, mean that there is no room for a discussion of ethical questions. However, these have to be evolved in the context of specific disciplines keeping in mind the fact that there is no such thing as a value free social science.

Hindrance to good research

Guidelines and Ethics Committee though essential, they should be such as not hindering good research.

Power dynamics

This draft takes cognisance of the inherent power dynamics that govern relationships between the students and faculty, the researchers and funders, the senior and junior members of a research team and attempts to address the issues that may arise as a consequence of this.

It was strongly felt that ethics and ethical guidelines on their own cannot solve issues where the researchers are mere small entities in a world of power and money. *Ethics without considering the role-played by power and money (essentially foreign agencies) may simply be futile.* These issues should be addressed. *The autonomy of the researchers needs to be made strong against conflicting forces.*

Comprehensiveness:

The guidelines could be made *less comprehensive*. It should have an introduction giving all relevant details followed by the guidelines.

In an effort to be comprehensive some issues about appropriate and rigorous methodology and competent research management have been brought under the purview of ethics. For instance, asking students or assistants to perform at a level beyond their training might also be considered bad management, bad supervision or poor training, rather than primarily an ethical issue. Though *such issues have ethical implications*, by bringing such issues in the guidelines the focus on ethics might be diluted.

Cultural sensitivity and specificity

While ethical principles are universal, *the procedures for application should be culture and situation specific.* Mechanisms for protecting participant's rights such as consent forms are developed in the UK or U.S.A. and are used in Indian field situations with disastrous consequences, often defeating the purpose they were devised for;

As newer public health challenges emerge within the Indian context such as the HIV/AIDS epidemic, there is a much greater need for debate and discussion on the ethical considerations related to research in this area.

Operationalising terms and phrases:
It is true that at some level all ethical principles are abstract and it may not be possible to clearly operationalise them. However, it may be useful to operationalise terms or phrases such as 'existing knowledge', 'risk minimisation', 'adequate knowledge', 'dignity', 'excessive amounts of time' and so on.

Language and editing
Use term institute instead of agency. There are many such changes needed. Besides, these are rules/guidelines, the terms specifying to what the operating parts are related to may be added (e.g. adding terms as thereto, therein, etc.). There are some repetitions, which need to be edited out.

Wider recognition and acceptance of code needed
Efforts must be made to get this code accepted by the funding agencies, journals, etc. This code should also be accepted and respected by the international organisations and journals.

SEPCIFIC COMMENTS ON DIFFERENT SECTIONS OF THE GUIDELINES

SECTION I: Preamble

General:
The preamble needs to be made stronger, raise ethical issues and be more critical, and give details in terms of the background. Moreover, *the exclusion of medical research needs to be clearly spelt out.* It should be more positive.

Purpose of the code maybe defined as:
(1) To improve quality, legitimacy and credibility of social science research. (2) To protect researchers from pulls and pressures of vested interests and dominant social forces. (3) To make research socially relevant so as to benefit a larger section of the society and to uphold human rights of the participants. (4) To evolve consensus for a need of ethical values among social science researchers for guiding their research so as to maintain autonomy of social science research.

SECTION II: Ethical Principles of Research

Provide *definition* of various terms such as "autonomy", beneficence", etc. and it would be good to expand the first paragraph by giving some more information on what each of the five normative principles actually mean.

Is there a *prioritisation or hierarchy* of principles? What to do when two principles are in conflict with each other in a particular instance or on a particular issue?

II.1 Essentiality
It is easy to state but practically difficult to achieve the requirement that the research should be undertaken after giving adequate consideration to existing knowledge because *it is still so*

difficult to access much of the available research. Access through Internet is limited to a few journals particularly from developing countries. Lots of research from our country does not get published due to the bias towards positive findings and lack of sufficient number of good social science journals. Is the unpublished research covered under "existing knowledge"?

II.2. Precaution and risk minimisation

How much 'risk' in a research project is 'risky'? Whether and how to quantify this? More importantly, if risk is involved, what 'safety nets' must be in place to manage the risk? Perhaps every research study should have ways and means of anticipating and assessing risk and also managing risk. What is acceptable risk, and what risks are definitely not acceptable? What would be minimum risk and what would be maximum risk? Some of these may be spelt out and shared with the participants of each research study. In some way this code may specify risk in more concrete terms. Moreover, it is not necessary that all studies carry some amount of risk.

II.3. Knowledge, ability and commitment to do research:

Some people argue that a badly done research is unethical. Is this code taking such position?

Who will decide the knowledge, ability and commitment of researchers?

The fist part of the statement "While research .... as professionals" may be deleted.

Should research be done *only within* a researcher's field of expertise?

II.6. Non-exploitation

Most research these days, is funded. So budgetary provision should be made for the payment of some nominal fee to the participants. This is a regular practise in ethnographic work. The idea being that, if knowledge is coming out of communities, then those communities have a bigger right to the benefits and commerce of the knowledge than anyone else. What are the criteria for compensating the respondent for "loss of income" if he/she is not gainfully employed?

II.7. Accountability and Transparency

The code should define "reasonable length of time" (say range of three to five years) for preserving research record.

The "public domain" should be clarified. It should not include the state/government perception of "public domain". The responsibility of adequate efforts to make the results of the research public should be a part of the principle of totality of responsibility.

The effort to be transparent *should not* mean revealing the names of the participants.

How does one ensure public accountability? Clarity is essential for issues such as public scrutiny and public audit.

The researchers are sometime forced to go ahead with studies they do not agree with. In such situations, what can the researchers do as they need funds?

II.9: Public domain
Is it realistic to bring out *all research* to the public domain? What about papers which are just not good enough? Are they not rejected by journals during peer review? It might be good for bad papers not to get into public domain and get quoted/used by others. The word "all" should be reconsidered.

Why is it necessary to publish research? *What was wrong in not publishing it?*

II.10. Totality of Responsibility
The paragraph mentions 'products', which are marketed. Are we talking about commercial research? If yes, doesn't this take the discussion to a different plane altogether? Shouldn't the document also then discuss the ethics regulating the commerce in health care work - profit, charging fee, packaging and advertising, marketing, 'telesales' etc.?

SECTION III: Ethical Guidelines

III.1. Integrity of Researcher

III.1.1
The studies done in one country could have *implications in another country*. Therefore, the implications thus mentioned need to be left broad, or the second sentence may be expanded to "... even an entire state, country or the world".

III. 1.2
It will be good to have some rules regarding use of information in the NGOs. The whole area of 'parallel publishing' which doesn't come under the purview of copyright is very sticky. When issues such as the above are raised, such as misrepresentation, etc. it ends up being a personal issue between two contesting individuals, both of whose integrity is eventually compromised, and leaving behind rancour and bitterness. *The issue of copyright and ownership of data too need to be discussed.*

III.1.2.
Expecting researchers to anticipate and guard against possible misuse and undesirable or harmful consequences of research sounds *very unrealistic*. How can researchers actually prevent people from doing what they want with the published papers? How will researchers even know what is being done with their research all over the world?

III.1.3.
This principle can be over-run by the state, especially when the research is undertaken by public institutions or uses public funding. The state or its organisations (e.g. ICMR, ICSSR, etc.) can, sometimes, legally usurp this principle, by claiming to act as the custodian of the well being of its people.

There may be instances where *research results need to be kept confidential*. For instance where the results may lead to harm to participants.

The words "to be kept confidential" may be replaced with "when its findings are not shared with the scientific community and participants of the research for scrutiny, discussion and interpretation."

III.1.4.
Split this guideline into two separate guidelines. *Sensitivity is a very broad term.* How does one define it?

III.1.6.
The last sentence should read, "..... any other such practices", instead of "other practices".

III.1.7.
Instead of "historical" the word "old" will be more appropriate since only records of 100 years old can only be called as historical.

Researchers not only have the duty to protect historical records but to protect *all records*.

III.2. Relationship between Researcher And Junior Researchers/Students/Trainees

III.2.6.
This guideline needs substantial change. One should not avoid usage of an available resource. Suggestion: "A community may identified for long term interventions, provided the issue is decided between the community and the researchers in a manner that is mutually beneficial, and provided students are the owners of their own research."

This guideline against using a community for constant and long-term resource should also be made applicable to *all* researchers and institutions and not to just research by students.

Others
Details about ownership of data cannot always be laid down at the outset since it would depend on the inputs of the student or junior.

What can be done if their seniors get scholarship in other countries on the basis of papers done by students/junior?

Those junior researchers who are not in agreement with the philosophy and principles of a certain research approach *must desist from joining* the research team right at the onset.

Students should be made to stretch their abilities to cover aspects of research such as conceptualisation, formulation of innovative approaches, original analysis, and delegation of work to them should not be merely task oriented.

The guideline sounds like allegations on researchers! A guideline on mutual respect needs to be added.

III.3.Relationship between Researchers and Participants

III. 3.2.

Instead of saying 'should not' can we be positive and say what can be done.

This is very general and may be further specified. *What is the bottom-line for 'harm' - physical and mental?*

Research *should not be undertaken* unless some actual anticipated benefit accrues.

Sometimes research may harm the dominant sections of society exposing their power and manipulation. Such research may affect their physical, social, psychological well being, though it helps the larger society. What is to be done?

When a researcher undertakes a study on certain critical issues, e.g. gender, the researcher inevitably influences the participants. Would the implications of this be in consonance with this guideline?

III.3.4.

Add word "thereof" (after "reason") at the end of the last sentence.

III.3.5.

How does one decide what are "unrealistic benefits"? *What should be a reasonable benefit?*

How does one *compensate*: actual compensation of the time, a certain percentage more than the actual opportunity cost? What should one give to unemployed people? Anything given to them would be excessive.

What is meant by excessive reimbursement? How much is excessive?

Are we accepting the concept of reimbursement? It may influence the participants to give you what you want.

There indeed is a dilemma about not giving anything in return to the participant when he/she has spent 2-3 hours in interview. The foreigners introduced the idea of reimbursement/ compensation and now respondents demand that from us.

III.4. Rights of Participants: Informed Consent

III. 4.2.

Add the following:

"The briefing given to the participant should be such that the participant comprehends that: (i) She/he is participating in a study. (ii) She/he has a right to refuse to participate. (iii) She/he will not be denied access to any services/information if she/he refuses to participate in the research study."

There is a need to devise *simple and culturally appropriate consent procedures* to protect the rights of participants. The key issue here is the participants' understanding of the consent process.

If, after an evaluation, one found that members of the community participating in a research did not know the objectives of the research, would it be ethical to terminate such a project after an evaluation?

III.4.4.

What does one do when funding agencies make it essential for researches to get 2-3 pages long informed consent signed by the participant?

Some medical researchers strongly expressed their disagreement on the idea of *not taking written informed consent* from the participants for the social science research in health. Sometimes the funding agencies demand a proof of the fact that consent was taken in terms of signed consent forms.

Should the participants be given a right *to withdraw at any stage* of the research, as such right has the *potential to jeopardise the entire research endeavour*?

There may be problems in respecting participant's right to get help. All researchers and institutions may not have *capacity and resources* to provide for such help. What is *the level* up to which the researchers and institutions should provide help?

III.4.6.

What length of time for interview or data collection from the participant is *excessive*?

III.4.10.

Are children defined here as *legal minors* (under 18 years of age)?

How can one try to get consent of child who is too small? Maybe *a cut-off year* for those children for their own consent is not needed could be specified.

Others:

For a longitudinal study, a *community board* with members from the participant group should be set-up.

Research findings *should be shared with the participants in a simple way (summary of findings, in the language they understand)*. In the briefing given to participants for getting informed consent, the promise to bring summary of findings to them may included.

III.5. Rights of Participants: Privacy, Anonymity and Confidentiality

III.5.3.

Is it really possible to devise "appropriate methods to ensure privacy at the time of data collection" in the kind of situation prevailing in Indian household and villages? People often have different conception of privacy.

III.6. Data sharing and Secondary Use of Data

Restudy at different points of time to see the changes; or restudy with different purpose or method of the same population is important to maintain checks on researchers arbitrariness and sole propriety. Sharing of data is then important. If the data/notes are not shared for scientific / study purpose, there is no mechanism left for verification and cross checking.

III.7. Reporting and Publication of Research

III.7.1.

There is a reference to *plagiarism.* It is important to list, to the extent possible, all things that can be treated as plagiarism to facilitate understanding. Moreover, plagiarism is linked formally to issues of *copyright and its violation.* However through the rest of the document there has been no mention of copyright or about 'ownership' of information. In fact in many of the activist circles there is a closely upheld view that knowledge is for everybody and we don't respect proprietorship over ideas. What then constitutes 'plagiarism'? What constitutes correct use of information and how to strike an ethical balance about use and abuse of information without falling into the trap of saying that only copyright laws can regulate.

III.7.3.

Authorship credit based only on contribution towards writing may be *unfair* to those who might have played extensive role in conceptualisation, analysis and interpretation. It should be recognised that *conceptualisation, formulation of innovative approaches, original analysis and interpretation also constitute substantial contribution.*

Many NGOs/institutions are involved in intervention/action research. In such research, the authorship credit should also be given *to key individuals who have participated at the programmatic level in operationalising the intervention*, but may or may not have directly participated in writing or analysis.

III.7.4.

The research results conveyed may be truthful and honest, but the media could still sensationalise them. What to do in such situation.

Others

Sometimes similar articles by the same author(s) are found in 2-3 journals.

The abstracts of studies should mention clearly the scale of the study. The content of paper should match its title.

III.8. Role of Editors

Why should the guidelines for social science research include guidelines on the role of editors?

The document *vests the editors with tremendous and almost final responsibility in ensuring the ethical norms adhered to.*

Guidelines given here are *too general*, they should be made *specific.*

III.9. Role of Peer Reviewers/Referees

The document *vests tremendous and almost final responsibility to peer reviewers and journalists in ensuring adherence to the ethical norms.*

Add guidelines *laying down the qualifications* required of those individuals who undertake the peer review or act as referees. At least it should be stated that they should have sufficient knowledge of the issue of research to be reviewed. Or the researcher should accept to be peer reviewer or referee for only those issues/topics of research for which he or she has sufficient knowledge.

III.9.3.

It may not always be possible to know about a potential or an actual conflict of interest at the start of the review.

III.8.3 and III.9.4

While the editors and peer reviewers should bring to the public notice the unethical research, malpractice and fraud, they should also *ensure complete anonymity to those who provide such information to them (whistle blowers).* This would not only protect team/institution members, but would also encourage more people to come forward with information.

III.10. Relationship with Sponsors and Funders

What to do when funders/sponsors lay down restrictions on publication of data or demand that their permission must be sought? Often institutions sign an MOU with the funders/sponsors to keep results confidential. Researchers need resources for their work, how could the resist the pressure from funders and sponsors all the time? Would bringing research results under the right to information legislation help to overcome such situations?

Section IV: Institutional Mechanism for Ethics

[Many conflicting comments have come on this section, expressing scepticism to regulatory implementation as well as making strong case for rigorous regulations. Some comments suggest that the implementation of code should be left to the conscience of researchers. Some would like to think and discuss more about the institution based ethics committee before saying anything on implementation mechanism. Some have demanded central or national ethics committee appointed by some authority or associations of social scientists or of social science institutions. Some have stated that the "self-regulation" might not work or hasn't worked (otherwise why the need for this code?) in our condition, so it is necessary to have structures with definite powers to implement the code. It is also argued that if this code would be followed by only those who have already been doing so (the ethical, the converted), then what is the point in so much effort being made. It must have utility in regulating those who are not ethical enough, and hence the need for some universal implementation mechanism.]

IV.1.

If the purpose of the draft is to set the code of conduct for social science research and leave it up to the individual researchers to *self-impose* them, the draft is fine. The draft, however, outlines the role of the institution to enforce the code. In this connection, the issues discussed are intricate and need a lot of thought.

Specifically *the question of an Ethical Review Board/Ethics Committee (ERB/EC) brings up the question of values and ideology in social sciences, and indeed the question of academic freedom.* The very idea of an ERB/EC in today's context in India (and the world) seems rather ***disturbing***. In a situation where the very principles of academic freedom are being eroded either by dominant and hegemonic groups or by the more impersonal but nonetheless real forces of market, one has to be even more cautious when suggesting an ERB/EC. One is not even going into the implementation of it and whether such an ERB/EC would in practice be able to rise above the fray and be "impartial" is altogether another matter. Given that; the agendas of social science and health and medical research are being increasingly set by funding agencies and corporations, one wonders whether these ERBs/ECs will indeed be able to interrogate the agendas of funders. Here we need to keep in mind our experiences about professional bodies. National bodies like the ICMR, ICSSR, ICHR, etc. were set up with the idea of protecting the autonomy of the profession and that of the researchers. However, their autonomy has been seriously eroded over the last few decades and today, those bodies are a pale shadow of what they were.

The 'voluntarism' underlies the document. This must be debated carefully so that the whole terrain is laid out before the group. After all, the need to spell out the code has been because there is the perception that voluntarism hasn't worked.

Some institutions might endorse the guidelines (and might network among themselves), but many others might not. Besides, the commercial market research organisations are unlikely to endorse the guidelines. It is possible that those not endorsing are doing lots of research and lot of that is unethical. What could we do about that? *For the code to be effective, all* *organisations and individuals doing any kind of social science or health research in this country must implement the guidelines.*

This code should be sent out to organisations doing lots of research but not making it public. *The results of all studies done should be brought under the right to information.*

A central or national committee, appointed by a social science association or by social science institutes, may be formed.

Localised body is more suited to our country due to diversity of culture and complexities of problems.

IV.2.
What role would the ERB/EC play- educative, consultative or regulatory?

If there is a central authority created, then *its role should be educational and consultative.*

The institution should have administrative control over the ERB/EC, as without that the recommendations of the committee may not be implemented.

Although the institution appoints the ERB/EC, it should be free from its administrative control.

ERB/EC should have members from within the organization as well as outside. A layperson from the study population as well as a person from the legal community should be on the committee.

IV.3.
The word "all" should be reconsidered. What about retrospective research based on records, etc? Should they go to the Ethical Review Board (ERB) or Ethics Committee (EC)? *If everything came up for ERB/EC review, this would lead to a lot of delay in a busy research institute or hospital.*

At what *stage or stages of research* should the ERB/EC undertake a review? Would not undertaking a review at all stages of research end up in the project bearing the time cost? Should not the committee be given the maximum time within which it should complete its review?

The ERB/EC *should have power to impose sanctions/punishment* on the institution and researcher for failing to observe ethics as given in the code.

What happens when the institution refuses to accept or implement recommendation of ERB/EC? For instance, *if the EC felt that on ethical grounds a particular research should not be undertaken but the organization feels that the project should be taken up?*

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CEHAT
(Research Centre of Anusandhan Trust)
2nd Floor, BMC Bldg., 135 Military Road
Next to Lok Darshan, Marol, Andheri East
Mumbai 400 059. India
Tel: (91)(22) 851 9420, Fax: (91)(22) 850 5255
Email: cehat@vsnl.com

BACKGROUND PAPERS

BACKGROUND PAPER: 1
Draft Not To Be Quoted

Ethical Responsibility in Social Science Publishing

Role of Editors, Journalists and Peer Reviewers

Padma Prakash

It is common sense that ethical codes of conduct cannot be effectively implemented in isolation. No one sub discipline or even a sub-discipline can hope to either evolve or put in place ethical guidelines for its practitioners. On the other hand, universal guidelines are more often than not observed in the breach. For, codes of conduct may be enforced in several different ways. One, is to conscientise the members of the profession to observe the rules, second, is to effectively police the system, and a third is to create links with associated disciplines or community of practitioners who together can form a network of conscience keepers. Journals and publications play this supplementary role in ensuring adherence to codes of ethics, even as others play a role in evolving and implementing a code of conduct for their own profession and trade.

It is hardly necessary to point to the crucial role that publications and journals play in the disseminating of the products of research. In so far as the process of research today is increasingly enriched by, even dependent upon, the articulation of the findings of research and their communication, to the rest of the academic community, to the people at large, there can be no research without its publication .

Journals are portals through which research activity and one might say by extension, the research community finds a voice. The primary and major responsibility for ensuring that ethical norms are followed in the social science research, lies with the researcher/s. All others who are touched by the research and are involved with any stage of it- institutions, journals, peer reviewers, editors, popular media- may play only a secondary role. Given this, the ethical responsibilities of editors of research journals is a reflection of the level of understanding of ethical responsibility within the research community. Having said that, it needs to be stressed that the disseminating medium of publication of research results plays an important supportive role. Journals and their editors can be seen to be conscience keepers for ethical research. However, in so far as they are also members of the press, their conduct must adhere to the codes of conduct of their profession. Journals play an important role expanding and fine tuning ethics in research and in journalism. Editors of academic journals are doubly accountable. There are however severe limitations to this role. Should they for instance, be whistleblowers? Should journals become a clearing-house for ethical misdemeanours? Given that they are the portals through which all research must pass in order to be accredited and acknowledged, should journals and their editors attempt to locate, separate and make complaints about and keep track of unethical conduct?

Essentially, the role of academic journals is to nudge researchers and research institutions towards ethical conduct. Journals cannot take on the responsibility of policing social science research. Firstly, they neither direct nor administer research. They are players only at the last phase of research. Secondly, their project is different--it is not the creation of knowledge, but its dissemination. While the manner in which the knowledge accumulation takes place is of importance, the journal's concern is with its readers, its contributors and with the expansion of knowledge base in the discipline/s. Thirdly, material published in a journal has to satisfy many criteria and not just in matters of ethical conduct of research. Fourthly, insofar as they receive a wide range of research contributions, they may be able to keep a finger on the pulse of research and its conduct .But this role is entirely dependent on their interaction with and their significance for researchers and research establishment. A journal of repute may be better able to play to play this role than a new journal or that has not for one reason or other gained a large readership in the academic community. This may be facilitated by creating a consensus among research journals on such issues as ethics in research. [See sections of the code]

I: Norms of Publication

In India journals which are not run by professional associations are few . The latter are bound by the codes of conduct of the association as much as by publishing ethics. To that extent it is easier for these journals to formulate norms and procedures that ensure that unethical social science research does not get published and disseminated. However, independent journals need to evolve codes, which draw from several disciplines. While these may not clash, the application of one set of 'dos and don't s' may not be advisable for another. Papers are accepted for publication on the basis of a number of criteria, which are different for different journals. But in all circumstances the decision rests with the journal.

Not all journals are entirely peer-reviewed. This may be because journals may have on their core staff, professionals from various disciplines. Or it may be because the periodicity of these journals and the number of papers they receive is such as to make the peer review process for all papers impossible. It could also be because, they include sections devoted to current affairs, where peer review cannot be a norm.

The time period between the receipt of a paper in a journal and its publication varies widely among journals and for disciplines depending on various factors including periodicity of the journal. It may be as little as two weeks or as long as a year. It is not widely known that the publication of an article is dependent on a number of factors: its topicality, its shelf-life, length of the paper, subject of the paper, and so on. However, the time between the submission of a paper and its processing is determined by fewer factors and typically, an author gets to know the status of a paper within three months.

It is important to recognise that most academic journals are short staffed! Like a teacher confronted with a pile of term papers, editors too resort to ways and means of making their work faster and more interesting. One practice followed universally is that the inarguably better presented and very evidently, better organised paper first from the lot of papers received more or less at the same time. It is important to remember this, because editors/peer reviewers are not infallible, nor can they play god. However codified are the norms of ethics, there is room for slippage.

Several considerations operate when processing a paper submitted for publication.

How interesting is the topic of research? Is it of relevance--to the discipline, to society? What purpose is it supposed to serve? Is the construct of the hypothesis mischievous, deliberately biased? How good is the work being presented. Is it academically rigorous? Is it scholarly? Has there been adequate literature survey? Does it academically, reinvent the wheel? Ethical issues pop up within all these considerations. It has been said many times that bad research is also unethical. So a paper rejected for lacking rigour may well have not followed ethical practices. On the other hand all research that follows ethical norms may not necessarily be found acceptable by a journal for other reasons.

Can a review process for publication spot fraudulent research? This issue has come up for much discussion following the publication of Alan Sokal's article and his attempt to 'expose' what has been called the lack of academic rigour in social science publishing. [See EPW issues of 1999. Website: www.epw.org.in]

II: Ethical Issues

Plagiarism

The term originates from the Latin word 'kidnap'. In the broadest sense plagiarism deals with the lifting of text/data from a source without crediting the source. However, the issue of plagiarism abuts on issues of copyright. Codes of several professional bodies have very specifically dealt with plagiarism and have defined it in different ways.

A journal or a publishing house plays a crucial role in ensuring that authors do not get undeserved credit for work that is not their own. In due process, plagiarised text is not very difficult to identify. Normally, in any journal or publishing house, the manuscript submitted for publication is read by a person who is in touch with the work in that field. Even so, while plagiarised writing may be relatively easy to spot, it is far more difficult to spot plagiarisation at the research end. Has the data been lifted from earlier documents? Have arguments evolved and presented included in the text without acknowledgement? These sort of details are far more difficult to spot. And with the rapid expansion of academic activity and the number of sub disciplines it has spawned, this could be a problem.

One way to deal with it is to send the manuscript to more than one referee, so that the likelihood of plagiarised text coming to light is enhanced.

What is the responsibility of the journal and its editors? Other than sending the paper back to the author, does the journal pursue the matter and make the information known generally? Does the journal inform the author of the reasons for rejecting the paper--that the journal has recorded that material has been lifted from other source without acknowledgement? Does it inform the original author of the attempt to plagiarise if her address is available? In other words, apart from ensuring that plagiarised material does not appear in its pages, can the journal ensure that the paper does not appear anywhere? Should it take on this role at all?

For the present there is little the journal can do but to inform the author of the paper the reasons for the rejection. But there is no supervisory body to which it can send a general alert. Nor do professional associations in India have a 'clearing house' or adjudication process for such issues. Nor is it possible to send information to the original author systematically or routinely. And then again, the journal has insufficient information to sit in judgement. For instance, it could possibly emerge that the first author had in fact lifted from the second paper, but due to a combination of circumstances, the first got published earlier. For this there has to be a process that compares the two papers and arrives at a decision. We do not as yet have such a process in place.

Sometimes though, especially in periodicals, which have sharp deadlines to keep, plagiarised papers do get into print. What happens then? Usually, such a paper is spotted within weeks of publication.

And the journal may be informed of it either by the original author or by another reader. In such a case there would be copyright violation and the journal itself stands to be charged with it [see below on copyright].

For the present, one can only state that if plagiarism is not as common as it could be it is only because ethical considerations do operate at the level of research. Several professional associations charge their members with responsibility of ensuring that they do not plagiarise. For instance the American Psychologists Association warns its members:

> *6.22 Plagiarism: Psychologists do not present substantial portions or elements of another's work or data as their own, even if the other work or data source is cited occasionally*
>
> .... *Psychologists take responsibility and credit including authorship credit, only for work they have actually performed or to which they have contributed.*
>
> *[... 6.24 Duplication Publication of Data: Psychologists do not publish, as original data, data that have been previously published. This does not preclude republishing data when they are accompanied by proper acknowledgement.*
>
> [Code of Ethics, American Psychological Association: Ethical Principles of Psychologists and code of conduct]

The American Anthropological Association admonishes its members not to " deceive or knowingly misrepresent (i.e. fabricate evidence, falsify, plagiarise) , or attempt to prevent reporting of misconduct, or obstruct the scientific/scholarly research of others."[Code of Ethics of the American Anthropological Association, June 1998]

The American Sociological Association has this to note:

> *14 (a) In publications, presentations, teaching, practice and service, sociologists explicitly identify, credit and reference the author when they take data or material verbatim from another person's written work, whether it is published, unpublished or electronically available.*
>
> *(b) In their publications, presentations, teaching, practice and service, sociologists provide acknowledgement and reference to the use of others' work even if the work is not quoted verbatim or paraphrased, and they do not present others' work as their own whether it is published, unpublished, or electronically available.[ASA Code of Ethics]*

Copyright

The Indian Copyright Act was first promulgated in 1911 and subsequently amended in 1957 incorporating the requirements of the Berne Convention, which India signed in 1927. A separate treaty under UNESCO was signed by the US and the former Soviet Union in 1952 which granted protection of only 25 years in contrast to the Berne convention which ensured protection to the author for her lifetime plus 50 years. The Indian act ensures protection to the author for her lifetime and 60 years after. With the signing of TRIPS in 1994, these conventions became infructuous. Amendments in the act in India in 1992 have been made including the right to formation of societies for monitoring copyright violations. While plagiarism is not mentioned directly in the act, it is covered in section 13(3). The problem is the issue of plagiarism has not come up for open discussion in the Indian academic community. This does not mean that plagiarism does not occur both in the mass media and in the academic media.

Today with the expansion of the media and seamless communication, it is far more difficult to monitor such offences as plagiarism. There is an urgent need for academic journals in India to get together on this and several other issues impinging on academic freedoms and unfreedoms.

Simultaneous publication/submission for publication:

Several professional associations in the west have specific cautions against simultaneous submissions. The ASA Code of Ethics for instance is the clearest in this regard and stipulates:

> *16.01(b)In submitting a manuscript to a professional journal, book series or edited book, sociologists grant that publication first claim to publication except where explicit policies allow multiple submissions. Sociologists do not submit a manuscript to a second publication until after an official decision has been received from the first publication or until the manuscript is withdrawn.*

This is the norm with regard to publication in the print media in general everywhere in the world including India. However, in India, the notion has clearly not caught on. Sometimes, though not rarely, authors submit papers for publication to two journals, without mentioning that information in either submission. This is a serious offence and must be considered to be so because it can lead to simultaneous publication of the paper leading to copyright infringement problems.

However, there is genuine confusion among academics on this matter. Is it incorrect to submit material for publication to two publication, one a condensed version and another the longer paper? Is it wrong to offer a paper to two publications one of which, is a small circulation journal with possibly a specialist readership?

There can be few blanket rules here. Overall simultaneous submissions are to be avoided. However, there could be an extraordinary reason why a paper or a part of it be submitted for publication to two journals. It could be because the publication of the full paper may take some time in an academic journal, while the content of the paper needs to be available for wider dissemination immediately, either through the mass media or through specialist journals or as a pamphlet. In all these cases, the author should inform the editor of the circumstances and seek permission, which may be given at the discretion of the editors in the interest of wider dissemination. Ways and means may be sought to overcome copyright problems. But in any case it is the responsibility of the author to inform the editors of the act of simultaneous submission.

Authorship and Publication Credit

Currently while some journals prescribe the manner in which authors names should be presented, there appears to be no norms for ensuring, at the time of publication, if indeed credit for work has been apportioned justly in the taxonomy of contributors in a particular article. The International Committee of Medical Journal Editors (Vancouver Group) has recommended norms for scientific authorship. But even this is not followed. There has been much debate about this issue in the pages of scientific journals. Some years ago, when the issue of by lines in scientific publications came up for much debate, *the Lancet* conducted a review of its published contributions and found that only about half satisfied the Vancouver Group criteria.

Ensuring that correct credit is given is important because as the Lancet pointed out during these debates, this is an issue of accountability. It is a question of, "who stands behind the word". Some journals in response to the anxieties of the scientific community instituted certain norms. The *British Medical Journal*, *The Lancet* and the *Annals of Internal Medicine* seek statements from the contributors on the nature of actual contribution of all the authors listed. The BMJ also asks for a guarantor to "ensure the integrity of the research".

Authorship has received considerable attention in several codes. Most professional associations stipulate that credit, including authorship credit should be given to all who have contributed (for example the ASA Code of Ethics). However, this may open to discussion. CEHAT's own internal code stipulates that authorship be given only to those who have actually contributed to the writing of the paper. The proposed draft code sets out the issue in broad terms and strikes a good balance, by including the proviso that all those who have contributed, including those who have worked for short duration etc should be properly acknowledged.

The Indian academic community appears unaware of these issues. Authorship norms vary among institutions. More often than not, authors are listed on the basis of seniority in the department rather than on the actual work done. Unless journals ask, as the Lancet does, for details of contributions of individuals, it is impossible to right a wrong in this matter. For example, it is well known and accepted that if a paper uses the work of a student, then the student should be the main author. This is not universally followed. Since this is easy enough to determine because of citations of the research work of the student, what should journal do in these instances? Currently in the absence of such codification in professional associations, journals have no grounds for suggesting a change in the order of authors' names. Ethical guidelines as are being evolved must incorporate recommendations on this count so that it is possible for journals to ensure adequate credit is given to researchers.

These above are patent and obvious problems for dealing, which there is sufficient documentation and even codification. Just what procedure one adopts can only be left to the journal. There are however a number of other issues which impinge on un-ethics, but may well get dealt with if the academic standards sought by the publication are stringent enough.

There are other issues with regard to indifferent research, which impinge on ethical practices.

III: Lack of Rigour Affecting Ethical Conduct and Reporting

Issues with regard to data

The data base in any dissertation, especially in one which is an empirical exercise, determines by and large the quality of the analysis.

Poor data may be a result of genuinely poor research expertise. But insofar as poor data may give rise to misleading information and understanding, it must be regarded as a matter of ethical consideration.

Editors/refrees cannot ignore the following:
1. Random sampling which is not in fact random and is deliberately biased
2. Either too many discrepancies within the body of data gathered or too few, matching all the expectations of the study perfectly.
3. Use of old or obsolete data for comparisons, when later sets are available

4. Inappropriate time frames for gathering data . eg data on illness episodes draw on only in one season used as universal data and overall conclusions drawn.

This is poor research, which is also unethical.

Informed consent

Often papers do not indicate whether or in what manner the population under study has been informed about the study. Nor if the researchers have ensured that people concerned donot have any objection. This is perfectly within the contours of a good paper, which does not necessarily state that each and every ethical norm has been observed. This being the case, while it is important to ensure that the work submitted for publication has abided by the norms of ethical research, it is difficult to be certain that it has. The best a journal can do is to look for associated indicators of good ethical practice. (see below). However, papers do sometimes that the issue of obtaining consent from a population or group under study has not even been considered. Then it is useful in the interest of ethical research that the journal seeks information about it. Whether or not research that violates some norms of ethical practice should be accepted for publication on the strength of its research content, for the new understanding that it brings to bear on a certain area of study is an issue that needs to be discussed within the community of academic journals.

IV: Check list for Editors/Refrees

In considering a paper for publication, it is not always possible as we have seen to find out, leave alone ensure that norms of ethical practice have been respected. While a ethical guidelines may make the task easier, researchers are not bound to submit any assurance that the research has been conducted as per the norms of ethical practice obtaining in the profession/department/institution. But it is often possible to look for indicators of good practice, and editors often do. For example, papers coming from certain institution prompt a more positive reception than others, often perhaps because the institution has a reputation for undertaking good research. If journals have a check list which covers some of the major considerations in ethical research, this may over a period of time encourage research institutions to not only adopt ethical guidelines but also to codify norms and practices for the institution with regard to the conduct of research and its presentation. The check list is however just that--it is not a decider. A first such check list is given below

1. Has any attempt been made to disseminate the results of the study to the study population?
2. Has care been taken to ensure the harm [1]has not accrued to the population as a result of the research?

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[11] There are many definitions of 'harm' in the different codes. Essentially, as far as journals are concerned they need to ask if any immediate and visible harm done because of the study.

3. Does the institution under which research has been conducted has in place an research ethics committee of any kind? Is it operational?
4. Are peer review processes in place in the institution. In particular, is publication submitted for publication subject to peer review?
5. Has the paper taken adequate care to ensure that the participants in the study have not been identified by the use of markers or other means? [2]
6. Have the people affected by the research understood and consented to the research? Or, does the institution have the practice of obtaining such consent for its research?
7. Principle of exclusion: as a thumb rule which gives some indication, who has been excluded in the study? Which population group has been deliberately included? Is there a reasonable explanation offered for this? [3]
8. If the research is independently done, outside institutions and is privately funded, has the author offered information on ethical considerations followed? Or has the funding agency adopted codes of conduct for research?
9. Language: Does the paper use abstruse and convoluted language or jargon when the same would have been conveyed in simpler language? [4]
10. Are there too many gaps in referencing ? Are the citations incomplete? [5]

V: Popular Press

The paper would be incomplete without some reference to the popular press. There is a wider gap between the popular press and the academic terrain, and presents far more issues, which need to be discussed in both communities of professionals.

Many of today's senior journalists in the press are academics who by their training and more often than not, their years of work, are as much members of academic community as they are professional journalists. This puts a double burden of responsibility on them. And there are manifest tensions between the immediate objectives of the academic community and the press. An accepted norm within natural science and technology disciplines is that 'discoveries' and research outcomes are not revealed to the 'general' public before they are presented to the relevant academic community either through

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[2] The Code of Ethical Conduct for Research Involving Humans (Code formulated by the Tri-Council Working Group) in Canada for instance specifies: "Researchers should not publish any part of their research that could lead to inadvertent identification of individuals." Other codes also specify such practices. The draft code suggests : "III.5.6...As far as possible the publication should give only the relevant information and avoid giving markers that might lead to the possible identification of the participants."

[3] The Tri-Council Code suggests that " women should be represented in proportion to their presence in the population affected by the research" which rule may apply to other groups and communities within the study population.

[4] Language is used sometimes to cover up indifferent research and lack of rigour and is a good rule of thumb, though it cannot be a decider. Also since the business of a journal is dissemination, there is reason to be sensitive to convoluted language.

[5] Incomplete referencing should prompt a doubt in the editor's/refreee's mind that the author may not know the work cited very well. This also applies to text which is incomplete or in obvious ways misquoted.

papers presented at seminars or published in disciplinary journals. In the social sciences this distinction is not so clear. In fact on the face of it there seems to be very little room for observing such a practice.

However, it must be stressed that the publication of research outcomes of social science research, and especially in health and health care, which has not been subject to peer review or the scrutiny of the population under study can be harmful, misleading and may even be dangerous and certainly unethical. Journalists and editors working in the popular media have a special responsibility to ensure that there has been adequate opportunity for research results to have received peer attention.

It may be noted here that there are cautions here for the researcher as well. For instance, the Code of Ethics of the American Anthropological Association states that anthropologists in publishing their work "are not only responsible for the factual content of their statements but also must consider carefully the social and political implications of the information they disseminate. They must do everything in their power to insure that such information is well -understood, properly contextualised, and responsibly utilised" (emphasis mine).

The draft code also suggests "III.7.4 ...Researchers who choose to do so [publish or disseminate their research results in the popular media] have a special responsibility to ensure that the ethics in research are not disregarded and the results of research have been afforded a peer review. Journalists and the media that publish these research results have a responsibility to publish the results truthfully and honestly".

This is an important part of the code and needs to be widely emphasised. Especially with the growth of social science research especially in health, especially impinging on policy affecting the lives of people which do often need wider dissemination even before they are published in academic journals.

The draft guidelines puts great weight by dissemination of research results to the affected or involved population and social scientists in their capacity as journalists and editors in the popular press need to acknowledge that if the study population has not been told the research outcomes, then the research may not deserve the kind of publicity which will accrue from its publication in any form in the popular press.

With the easy availability of international academic journals on the world wide web, there is an increasing tendency, especially in health and medicine, to cull information from published academic papers. It is best in fact to allow for discussion to develop within the academic community on particular papers before reporting the research in the popular press (unless of course if there has been a press conference and even then journalists should check if there has been adequate peer review). In the event of there being an urgency to report the research, then it is imperative that the journalist should conduct an independent 'peer review' of sorts eliciting the opinion of other academics in the field. Today with modern means of communication, this is not at all difficult.

Similar cautions should be exercised in writing up interviews. Cross-checking facts/data with the interviewee is necessary in all disciplines not only in the natural sciences and technology.

There are today in India associations of journalists specialising in science or in environmental issues. But have done little towards clarification of some of the issues mentioned above.

VI: Role of editors in cyberspace

Between the time this paper was commissioned and now I have come to realise that the vast new communication media opening up through the internet is completely uncharted, with few signposts. There is very little in the form of legislation and copyright laws are being tested severely. In social sciences there at least three academic social science journals which are entirely on the internet. While they have processing norms for papers, giving that the medium allows for a more rapid turnover and response rate, it gives rise to a number of problems in publishing. These are only now being even defined. Moreover, there is little clarity on the norms for individual researchers to 'publish' papers, articles and even books on the internet on their personal web pages. Who governs this kind of publishing? How does the process of peer review apply here? Is this sort of publication itself in a manner of speaking, an opportunity for peer review? How do copyright laws apply? We need to recognise the fact that may make it more difficult to process. And while copyright laws are being evolved and codification is under way, it will take a while for norms and conventions to develop.

VII: What Needs to be Done?

Evidently, there is an urgent need to formulate code/s of ethics for academic publishing. A first step is in fact to build a consensus for evolving such a code. The code of ethics- however rudimentary- evolved by the various press associations could be a starting point and may in fact play a lateral role in reviving interest in strengthening a code of conduct for journalists as well.

An attempt must be made to create a space for communication among academic journals and their editors. So far academic journalism in India has been at a rudimentary level. Indian social science journals do not as a rule attract serious academic attention abroad for many reasons. One of these reasons is the uneven quality of academic presentations in these journals. If good, ethical and effective social sciences as academic disciplines are to grow, then social science journals need to review their performance. With increasing research output within India and on India and South Asia, there is a potential for specialist academic journals. Without a forum such as this, it would be very difficult to emphasise and encourage rigour in academic research.

Moreover, it must be kept in mind that in India there is a tradition of remarkable academic research in social sciences being undertaken by groups and bodies and individuals who have no affiliation to large academic bodies and who may be part of activist and political groups. While such research has played an important role in the continued vitality of the social sciences, there has been much discussion about its academic rigour and such issues as bias. This is a significant tradition, which often challenges dogmas and dominant paradigms within academic circles. If academic journals are to allow space for these while at the same time not fall into the trap of publishing 'biased' research or studies without adequate rigour, then we need to have a forum for discussing such issues and arriving at broad guidelines.

In conclusion, it should be apparent that codes, guidelines and norms do not in themselves make for good, ethical research. To quote the Tri-Council Code

Good ethical reasoning, like good reasoning in research, must be more than a matter of mechanical and dogmatic application of rigid rule to fact situations. Ethical reasoning requires thought, insight and sensitivity. As in research peer judgement is important. In the case of ethics, peers include more than fellow research participants. Ethics peers include the larger intellectual community and society at large, including research participants. [Report of the Tri-Council Working Group appointed by the Medical Research, the Natural Sciences and Engineering Research, and the Social Sciences and Humanities Councils of Canada, titled, "The Code of Ethical Conduct for Research Involving Humans"]

Editors comprise this larger intellectual community and play their role responsibly.

Ms. Padma Prakash
Senior Assistant Editor
Economic and Political Weekly

BACKGROUND PAPER: 2
Draft Not To Be Quoted

ETHICAL ISSUES IN
SEXUALITY RESEARCH AND INTERVENTION

Radhika Chandiramani
Lesley Jane Berry

This paper addresses some of the ethical issues encountered while working in the field of sexuality. It illustrates ethical challenges that arise in research and intervention in a country where the socio-cultural context is often inimical to the sexual and reproductive rights of individuals, especially of women. The paper is presented in five sections. Because this paper has been written as a background paper to the Draft Code of Conduct in Social Sciences and Health Research prepared by The Centre for Enquiry into Health and Allied Themes (CEHAT, 2000), it refers to the Draft Code where appropriate. Section I outlines the meaning, scope, and need for ethics in the field of sexuality. Section II looks at some specific ethical issues relevant to sexuality and sexual behaviour research conducted in India in the last decade. Issues of need for services versus competence of providers, and the concepts of confidentiality, privacy, and anonymity are discussed in the context of intervention, in the next section. Section IV illustrates ethics in practice on a telephone helpline, and, Section V reviews the Draft Code and adds to it points from other Codes of Ethics that enhance the usefulness of the Draft Code in the field of sexuality.

A brief introduction to ethics and its relevance to the field of sexuality

Ethics refers to codes of moral conduct that guide behaviour. Personal codes of conduct might be ill-defined and unarticulated but they still serve the purpose of guiding behaviour and influencing actions. However, professional bodies have articulated and codified their guiding principles into Codes of Ethics that serve to guide and monitor their work. All codes of ethics are based on ethical principles that may or may not be stated clearly but are implicit in each of the guidelines of the codes.

Codes of ethics are dynamic i.e. they are responsive to change. Therefore, they require periodic re-evaluation to ensure that they are in keeping with the times. For example, with the advances in electronic data communication and storage and the parallel advances in 'hacking', it is important that ethical statements pertaining to storage of data include suggestions on the safe electronic storage of sensitive information.

Historically, ethical principles that guide professional activities have been present long before any formal declaration of human rights. The Hippocratic oath that enjoins physicians to 'above all else, do no harm', pre-dates the Universal Declaration of Human

Rights (UDHR, 1948) by many centuries. Ethics as a branch of philosophy has a long and rich history. However, it has been the horrors of the Second World War and the excesses of the Nazi regime that finally pushed the world community to formulate statements to protect the human rights of all peoples. In turn, the concept of individual human rights has fed into the articulation that no research, whether physiological or psychological in nature, should violate the human rights of its subjects (Ringheim, 1995).

Human behaviour has always been an issue of great interest for social science researchers. How human beings spend their money, how they bring up their children, what they eat, what motivates violence, all this and more has been studied using different approaches. The fields of anthropology, psychology and sociology have distinct ways of looking at and interpreting human behaviour and life. These different fields have studied the sexual customs, behaviour, and relationships of people all over the world.

Sexuality has also been studied using medical and public health models. Though sexual behaviour has been a subject of study since the early 19th century, never before has it been studied with a sense approaching desperation as it has been since the AIDS pandemic hit the world. Perhaps few other subjects of social science research and intervention are as complex and challenging as is the study of sexuality, because of its enmeshment with individual and group identity, social customs and norms, religious beliefs, gender roles and expectations, amongst other factors. Sexuality is linked with notions of purity and chastity, shame, possession, cultural pride, and even national identity and statehood. All this necessitates the exercise of utmost sensitivity and social responsibility while engaging in intervention and research in sexuality.

With the increasing understanding that sexuality is multi-layered, it currently lies at the intersection of many fields including those of psychology, medicine, public health, sociology, anthropology, queer studies, gender studies and other emergent, and as yet unnamed, fields. As a field of study and action, it is inhabited by professionals from different disciplines, as well as by non-professional volunteers. Therefore, it is not yet but requires to be governed by an particular and articulated set of ethical guidelines.

In India, as in other parts of the world, most efforts to look at sexuality (whether from an applied research or intervention angle) are motivated either by a public health or family planning goal. Whatever be the underlying reason for undertaking research on sexuality, there must always be a valid, justifiable and clearly stated reason for doing so, or else researchers can very easily exploit and damage other human beings and be accused of having political, voyeuristic or other pernicious motives.

While conducting research or engaging in an intervention in the field of sexuality, it is also important to look at underlying theoretical issues and assumptions. An excellent resource on this is the work of Carole Vance (1999) and Gayle Rubin (1999). Unexamined assumptions may serve to perpetuate certain constructs. Ericksen and Steffen (1996) have found that the surveys of sexual behaviour they reviewed reflected dominant constructs of gender differences in male and female sex drive and behaviour.

Often one of the implicit goals of conducting research on sexuality is that of research findings and insights leading to the development of strategies that facilitate behaviour change, especially with regard to safer sex practices vis a vis HIV and other infections, and, unwanted pregnancy. In this context, there is a need for in-depth research that yields accurate information concerning sexual attitudes, negotiations and practices in order to build a holistic strategy for prevention. Vance (1999) emphasizes this with regard to the fact that at present the majority of HIV research occurs within the biomedical sphere. This perspective not only fails to adequately address complex issues of sexuality, but also serves to obscure them due to its underlying assumptions concerning the nature of sexuality. Therefore, getting back to ethics, it is important to consider the ethical soundness of conducting research that explores issues of sexuality, both in terms of the 'depth' of data obtained, and the research experience of the participants (eg. extent of rapport, safety and ease experienced).

Issues linking the goal of research to the methodology used are also significant. As Renu Khanna (1996) points out, " where empowerment of women and helping them gain control over their bodies is an aim, the research model itself needs to be a focus of attention. Participatory and action research models are better suited to facilitate empowerment as well as yield the good quality data we need. Research methodologies which draw on feminist principles of 'personal is political' and woman-centredness are also to be preferred while doing research with women on sexuality, gender and health". In line with this view, Holland et al (1999) provide an interesting discussion of a feminist investigation of young people's sexuality and illustrate how the researcher's feminist assumptions informed the process of research right from its conceptualisation to its interpretation.

Ethical principles

Ethical principles are concepts that underlie the more specific guidelines that are spelt out in codes of ethics. Codes of ethics attempt to, but realistically cannot address all possible ethical dilemmas that may arise in the course of work. Ethical principles contain the essential values or core concepts meant to guide the resolution of ethical dilemmas.

Ringheim (1995) makes a strong case for using the principles laid down by the Council for International Organisations of Medical Sciences (CIOMS) that apply to bio-medical as well as to social science research, to also guide research on sexual behaviour. The ethical principles are:

Respect for persons, which includes autonomy and the protection of persons with impaired or diminished autonomy

Beneficence, which means maximising benefits and minimizing harms or wrongs

Non-maleficence, which means 'do no harm', and,

Justice, which prescribes equal treatment for all.

Ethical issues arising in research on sexuality

After reflecting on the meaning and significance of ethics for the field of sexuality in the previous section, the focus is now on some specific issues that arise in the course of conducting research on sexuality. The issues focussed on here have been chosen because of their relevance to the current social and temporal context and are by no means the only issues that arise. The studies cited in this section are being used as examples to illustrate specific issues. All examples used in this section, were initially sourced from an annotated bibliography of research studies on sexuality and sexual behaviour conducted in the last ten years in the Indian context (Gurbaxani and Khanna, 2000).

The specific issues discussed in this section are:
Training in Sexuality and Ethical Issues
Methods of Participant Recruitment, and, Informed Consent
Considerations of Privacy during research
Issues arising from Cross-checking of data
Provision for Corrective Information for research participants
Data/information 'flight'
Potential scope of Review/Peer Panels

Training in Sexuality Research and Ethical Issues

Researchers involved with a project that explored rural women's perceptions and experiences of marital sexual relationships, participated in a month-long training program in order to instruct them on the in-depth interview method and to "desensitise them on topics pertaining to sexual behaviours and practices" (Joshi et al,1997). This was followed by a preparatory series of trial interviews in a different village. This is an important ethical consideration: researchers should be adequately trained for the specific nature of the research that they are conducting, as poor interviewing techniques regarding intimate subjects could potentially cause distress to participants. The training of researchers must include provisions that explicitly address these issues.

This study demonstrates methodological awareness of the need for sensitive, competent researchers to work with people participating in sexuality-related studies. Clearly, this is a major ethical consideration when designing projects, especially within local communities.

Methods of Participant Recruitment, and, Informed Consent

An ethical consideration concerning methodological techniques is the methods that researchers use to select participants. In a study conducted in a community, George (1997) states that local non-governmental organizations (NGOs) were requested to identify and mediate with community members suitable for the study. One NGO that facilitated this process was a marriage-counselling centre with clients in the area, which gave George "a list of people, former clients and other contacts whom we could meet and request them to participate in the study."

Although the disclosure of clients/contacts of local NGO's is a matter for their discretion, it is important to consider the privacy rights of individuals who are approached. As there is an inherent imbalance of power between the researcher and participant - which may inhibit a potential participant's ability to refuse participation - it must be considered as to whether this factor is enhanced if the researcher states that a specific individual or organisation known to the person recommended them for recruitment in the study. This initial request alone, or if a participant has a negative experience of any form during a study, may affect individual or community relations with the NGO associated with the study.

Therefore, in the event that an NGO wishes to assist a researcher in contacting potential participants, it might be useful for the NGO to first reflect on issues of contracts or assumptions of confidentiality that they might be operative in the minds of the people they work with. Maybe the NGO can itself initially contact potential participants to check whether they consent to having their identity revealed to the researcher and to being approached by the researcher. In the case of George's research, this appears to have not mattered too much as participants felt free to either drop out or continue with the study' and some later confided in the researchers that they were 'not in agreement with the NGO person who was the via media.

Associated with the issue of participant recruitment are issues of how consent is obtained. Is it free and informed? Quite obviously if participants are recruited through other agencies that offer them services, it has to be made clear that their participation or non-participation in research will not affect service provision. In some cases, where individuals may not be regarded as autonomous beings, the issue of consent becomes murky. For instance, if the village leader gives consent does it automatically mean that all the inhabitants of the village are agreeable to being research participants? Do they really have the choice to refuse? In this context, Gostin (1991) makes distinctions between individual consent, permission, and community consensus in the context of culturally appropriate agreements to participate.

Considerations of privacy during research

In a study conducted by George (1997), at times female respondents seemed uncomfortable during interviews held within their homes (because sexual matters were discussed), due to their mothers-in-law's presence in the house or the chance of their husbands returning home. This is a common illustration of the issue of privacy and confidentiality that must be considered when researching sexuality and sexual practices. Basu (1994) states that an ideal scenario would be to ensure that knowledge of an individual's participation in a study be kept from family members, both to avoid the "fear of disclosure syndrome", and to minimise spousal/family interference. Given the structure and functioning of Indian families and the life circumstances of people, this may not always be a viable option. Therefore, researchers need to consider the location of prospective interviews in order to minimise the discomfort experienced by participants, and also to anticipate and guard against any negative consequences for participants arising in the family.

Having said this, it is important to also point out that concepts of privacy are variable. This calls for researchers to be aware of privacy needs of people within local communities and be able to adapt to local requirements. Participants may sometimes surprise researchers by requesting that others be present during an interview. Flexibility of methodology and consideration for the ease of participants is evident in a study on rural women's experiences and perceptions about marital sexual relationships, conducted by Joshi et al (1997), in the fact that when respondents (17 out of 69) requested it, they were interviewed in the company of their husbands or friends. This was accommodated within the methodology by adopting a 'paired interview' technique and was not automatically dealt with as restricting research outcomes. Furthermore, personal interviews were also not tape recorded as some participants raised objections to this.

Issues arising from cross-checking of data

Closely related to the aforementioned issue is the consideration of privacy when cross-checking responses of research participants. This is especially important with regard to those studies that address the sexual attitudes or practices of married couples.

In such studies, researchers consider it necessary that the statements of married men be corroborated with those of their wives, in order to gain a higher level of accuracy and sophistication of data. This means that women are often interviewed after their husbands have become fully aware of the nature of the study. Can any specific methodology be employed to ensure that women do not become open to suspicion from their families with regard to the sensitive information that they are disclosing about their husbands? Several studies cite statements from male respondents indicating that they consider it inappropriate for women to initiate discussion regarding sexual matters. This suggests that caution should be exercised when approaching women to discuss these issues, and in disclosing to men that their wives have or will be interviewed on these matters.

Provision of corrective information for research participants

Ingham (1990) notes that when investigating sexual and HIV-related knowledge, attitudes, and practices, it is important to ensure that research methodologies that test empirical knowledge, e.g. in 'true/false' questionnaires, provide adequate opportunity for respondents to have access to corrective information on completion of the study. This issue is relevant with regard to both mailed and reader-response questionnaires, and with a range of interviewing techniques. In addition, Holland et al (1999) state “There were occasions when we were unwittingly doing sex education simply by asking questions”.

This issue applies to several studies. For example, a study conducted by Savara and Sridhar (1994) which seeks to establish respondents' perceptions of the links between sex and sickness incorporates a Yes/No response to the questions 'Do you think you can get sick because of sexual intercourse?', and, 'What type of sickness can you get: weakness/fever/STD's?'. The study does not mention whether participants had access to corrective information although it stated that "few respondents felt that sex leads to sickness". (Savara & Sridhar, 1994)

Similar concerns arise with studies that investigate sexual behaviour/activity through questionnaires published in national magazines. Should it be considered necessary that a follow-up article be published in the magazine giving results of the survey? This could serve the function of exploring the topic in further detail, therefore addressing particular themes or common misconceptions that respondents may have raised, or that may be apparent from data analysis. Details of organisations that readers may contact for further information or help could also be included. Have the researchers made any provisions for readers to contact them with queries? After interviews are over, the interviewer can leave with the interviewee contact details or some written material on the topic, if appropriate, for further information, and can clarify obvious misconceptions.

Data/information 'flight'

Ingham (1990) also raises the issue of 'ownership' of data in the context of researchers working on a temporary basis in different localities and countries. This addresses the ethical connotations of taking knowledge 'out' of a specific locality or country with minimal regard for reciprocity issues, particularly if the information generated has practical value for the population involved.

An example of considering reciprocity is a study conducted by George (1997). After the study, she used findings generated from a community-level study of AIDS and risk perception to conduct AIDS awareness programmes with two local NGOs in the area where the study was conducted. She noted that in asking community members to participate in the study their most common question was 'what will I gain from this?'. The formulation of the awareness programmes was one way that George used to actively address this issue.

The Draft Code makes no provisions for generating ethical accountability with regard to non-locals or non-nationals conducting and using research. This is an issue that, where relevant, could perhaps be raised with Peer/Review Boards.

Potential Scope for Review/Peer Panels

The CEHAT draft states that the input of review boards should be sought at "various stages of research" (III.1.5, p.3), and that review boards are responsible for "improvement and advancement of research" (III.9.1, p.5), and that in the absence of other professional monitoring bodies, Review groups or boards could be set up. These would be particularly useful in situations where researchers are exploring uncharted waters, for example in working on issues that are likely to affect local sentiments (incest, adolescent sexuality, etc).

Therefore the role of Peer Review groups could be specifically formulated to monitor the ethical content of studies in their preliminary stages, to some extent during the study, and especially during the publication and dissemination stages. While working with local communities, it would be wise to have a member of the community on the review board. This would not only ensure that researchers respect community sentiments at all stages of their work, but would also make the community more receptive to unpalatable findings, if any. The matter of presenting research findings back to the community from which data is collected is a serious issue that can result in unanticipated consequences. The manner in which findings are presented to communities must be sensitive to public sentiment and community needs. The review board would also have some influence in ensuring that findings from completed studies are used to the maximum benefit of any groups or organisations to which they are considered applicable.

Intervention and ethics

Interventions that seek to directly or indirectly affect people's sexual and reproductive health also touch many other parts of their lives. Conversely, people engaged in interventions that initially apparently had nothing to do with sexuality find themselves having to grapple with issues of sexuality. For example, a programme addressing Panchayati Raj issues with rural women may need to address issues of sexual and domestic violence or be privy to information illustrating the links between sexuality and politics. Clearly, it is not possible to anticipate all the places where sexuality might rear its head, but certainly those working in areas that have a high likelihood of this occurring must equip themselves for this eventuality. And those whose work necessitates their dealing with issues of sexuality, for example those who work on issues of HIV/AIDS, reproductive health, and domestic violence, must be familiar with the ethical principles stated earlier as well as with other issues that derive from those principles.

There are no clear-cut boundaries to demarcate ethical practice while working on sexuality issues with communities. There might also be competing forces at work that serve to further confuse issues for service providers. Cultural and social sensibilities are easily offended and any links with women and sexuality all too often exploited by political and fundamentalist forces to meet their own nefarious ends.

The culture argument is often used in opposition to the assertion of individual rights that include sexual and reproductive rights. The legal machinery also does not always keep pace with the rights discourse. For instance, marital rape is not yet recognised in the Indian legal system. Dominant social norms and values may be inimical to well-being and they pose a tremendous challenge to NGOs and others seeking to address vulnerability and oppression (Chandiramani, 1996).

Given the complexity of working on this issue, it is all the more crucial that work in the area of sexuality be above reproach or allegations of ethical violations. Because the field of intervention is wide-ranging in terms of the kinds of intervention that are made, and has fuzzy boundaries, it is perhaps not possible to delineate statements of ethics that can apply to all the work that is done. Nevertheless, it is important to be aware of over-arching principles that apply to all types of intervention.

The Draft Code focusses on research, not intervention. Some of the ethical guidelines for research apply equally well in the field of intervention, eg. informed consent. Interventions in the area of sexuality take many forms, including support groups, helplines, policy advocacy, public information dissemination, consciousness-raising, counselling, peer education, provision of clinical services, and so on. In this section we take a conceptual look at some of the core ethical issues pertinent to intervention that uses a counselling or allied approach. The issues are those of:
Autonomy
Confidentiality
Competence

Autonomy

All individuals are capable as moral agents of making decisions about their own lives. This principle is a corollary to the principle of respect for all persons and is what lies behind guidelines on informed consent. That all individuals are autonomous agents means that they have the ability and the right to decide for themselves what they wish to do, including the right to refuse to take a particular course of action. Autonomy also implies that NGOs and others cannot barge into people's lives with a 'we know best' attitude. Intervention in people's lives carries with it implications of unequal power - whether it is the power of expertise, medical authority or social power – and its potential of causing harm.

In cases where the competence of people to make their own choices is questionable, as in the case with people who are mentally challenged for example, careful consideration has to be given to the question of whose interests are being served by a proposed course of action. The case of hysterectomies being performed on mentally challenged women inmates of an institution so that it is easier for the institution to take care of their menstrual hygiene is a case in point (The Times of India, February 20, 1994)

Respect for persons also demands the exercise of being non-judgmental. It means not judging people according to one's own value system. Being non-judgmental does not imply being value-free. There may be instances in the course of one's work where one's values must be clearly voiced. While dealing with a perpetrator of sexual abuse, for example, if the values of choice and consent are not stated, the perpetrator might perceive silence as sanctioning abusive behaviour.

Confidentiality, Privacy, Anonymity

Confidentiality refers to the communication of private information from one person to another in a setting where it is expected that the recipient of the information will not ordinarily disclose the information to anyone else.

Confidentiality refers to not divulging information shared by an individual. Anonymity refers to the identity of a person not being known. The difference between the two concepts lies in the fact that in the case of the former, the person's identity is known whereas in the latter the person's identity is not known. These concepts derive from the principle of beneficence. In the interests of serving clients better, confidential information might be shared with team members or with other professional colleagues with the understanding that it is confidential and is being shared for a specific purpose - eg. making a referral, seeking supervision or peer support.

Confidentiality, especially in the context of material with a direct or assumed sexual content, cannot be emphasised too much. Because sexuality so easily evokes shame and guilt, and is tied in with social and cultural proprieties, it is essential that community workers, peer educators, counsellors, and others take all precautions to ensure that confidentiality is maintained. This is especially crucial while dealing with HIV/AIDS related issues. The possible consequences of breaking confidentiality can include social ostracism and even death.

Careless storage of documentation, other people overhearing conversations, inadequate privacy during a counselling session, naming clients, etc are some ways in which confidentiality may be jeopardised unwittingly.

Privacy and confidentiality are different. Privacy means having conditions conducive to engaging in a private act or conversation, something one does not want to do in the presence of others. Confidentiality requires that the contents of the interaction are not to be divulged. Adequate privacy does not automatically translate into confidentiality. Also, most often people need to be reassured about confidentiality and if there are limits to confidentiality, this must be made clear to them. Issues of privacy often take a backseat while working in community setting and even in public hospitals where space and time are at a premium. For example, people are usually not comfortable talking about their sexual lives in situations where others can happen along, as in interviews held in corridors or in a crowded room. Privacy does not require large rooms, it requires the exercise of common sense and sensitivity. The precautions of taking the person to a quieter and less crowded place serve to enhance feelings of safety and comfort.

Competence

Ethical practice demands that individuals receive the best quality of care possible in a given situation. This implies that services must be provided by those who are competent and who work within the limits of their competence. Competence demands skills and training. However, in the resource-poor settings of developing countries, the immediate demands of communities have to be met by using whatever resources are available. Consequently, interventions are often made by NGOs that do not have the resources to secure the services of trained professionals and/or do not for various reasons, engage in undergoing professional training. Ideological differences also contribute to NGOs not undergoing professional training in certain areas like counselling. Some people believe that professional training serves to perpetuate empires of expertise and increases the power imbalance between the 'expert' and the others.

That the issue of competence can be a major problem is clearly seen in the area of counselling. Counselling is a word used loosely in the NGO as well as the government sector. It is often misused as a synonym for giving information to, advising, guiding, and motivating people. Counselling, in a mental health context, has a specific meaning. In simple terms, it is the process of facilitating people to find what it is that they want to do, the process of enhancing the autonomy of the client. Activism and counselling are different processes, informed by different but sometimes overlapping perspectives, and require different sets of skills (Vohra, 1998).

One of the main areas of disagreement between professional and lay counsellors is the topic of boundaries between client and counsellor. Lay counsellors feel that boundaries are artificial and serve to increase the distance between counsellor and client, and they perceive this as being a bad thing in itself. Professional counselors, on the other hand, view boundaries as an inherent part of the counselling process that enables the enhancement of self-hood or autonomy of the client. Whatever the ideological merits and demerits of the two often conflicting positions, the practical implications of an absence of clear boundaries have ethical ramifications for work on sexuality.

Counsellors and case-workers may not be immune to obtaining vicarious gratification from their clients' accounts. A lack of clarity and discipline about boundary issues can result in psychological damage and/or sexual exploitation of clients. It can also result in a confusion between the counsellor's own needs and those of the client. End result: the client's issue are no longer of paramount importance because neither counselor nor client knows where one begins and the other ends. This is a simplistic but accurate portrayal of what can and often does happen when well-meaning but inadequately prepared individuals engage in 'counselling'.

Ethics in practice

Familiarity with ethical principles and guidelines is no guarantee against ethical dilemmas. In fact, along with a deeper understanding of the subject matter there is a greater appreciation of situations that present themselves as challenging notions of what is the most appropriate and ethically sound response. In this section we share some insights that we have developed from practice.

In sharing some of our ethical dilemmas and insights we hope to illustrate the tension between various competing forces that affect intervention in the area of sexuality. TARSHI (Talking About Reproductive and Sexual Health Issues) is an NGO that believes that all people, whoever they are, have the right to a life of dignity encompassing their right to sexual well-being, to a healthy, enjoyable and self-affirming sexuality. As part of working towards making this vision a reality, TARSHI runs a telephone helpline that provides women and men information, counselling, and referrals on sexual and reproductive health concerns. So far TARSHI has received calls from over 38,000 women and men between the ages of 10 and 70 years, since 1996. Trained phone counsellors handle calls on the helpline. All calls are documented for analysis so that findings can be used to ensure quality services and inform others working in the field. (For a fuller description of the functioning of the helpline and kind of calls received please see Chandiramani, 1998). Services are in Hindi and English, free, confidential, and callers are guaranteed anonymity.

In the section below we share with you some of the ethical challenges faced at TARSHI. In the interests of brevity we are sharing only those issues that have not been dealt with in earlier sections and those that provide a special illustration of an ethical guideline.

Research vs services

Given that there is a dearth of information on the sexual practices of individuals and that the helpline methodology offers a window into intimate areas of people's lives, there is a pressure to find out more about what people do sexually, with whom, in what circumstances, influenced by what factors, and how. There is a seduction in being in a position of being able to probe into people's lives, where both they and the counsellors are unknown to each other and yet are in a relationship of intimacy where callers can say things that they probably cannot say to anyone else. This calls for great discipline on the part of counsellors to stay tuned to callers' needs and only ask questions that are relevant to callers' concerns, and not to counsellors' research interests or voyeuristic impulses.

TARSHI has had to reflect on it's priorities, and we have asked ourselves whether better methodologies of research would interfere with the nature of helpline work. In very simple research terms, if we had data about the marital status of all callers for example, we could perhaps use this consistently as a variable in our analysis of data. Yet as matters stand, as a policy we do not ask about or assume marital status (unless it is directly relevant to the caller’s stated concern), because of the moralistic and heterosexist connotations attached to linking sexuality with marital status that would jeopardise callers’ sense of safety and ability to freely share their experiences and concerns.

Anonymity

The TARSHI helpline ensures anonymity to callers, i.e. it does not require callers to provide any personal identifying details about themselves. However, in order to make appropriate referrals to health care services, callers may be asked which part of the city they live in so that they may be referred to a facility close to their homes. Callers likely to call again are given code numbers for identification on subsequent calls. The principle of anonymity precludes us from receiving messages on an answerphone that might require us to call people back. This means that we 'lose' many calls from those who might have tried after our office hours or when the lines have been busy. However the reason we do this is that in addition to shifting the responsibility for the call to the helpline and not the person in need, it would also jeopardise the anonymity of the caller. Calling people back has the potential of arousing the suspicions of family members as to why the person is receiving a call from an organisation that works on sexuality issues.

In a lighter vein, the principle of anonymity also means that no caller identification technology is used despite the temptation to do so especially with obscene and abusive callers!

Responding to media requests

As a helpline that responds to people's concerns it is important that people know about TARSHI so that they can use the services offered. Media coverage is a good way of increasing visibility and credibility. However, we have had to exercise great discipline in our dealings with the media and anticipate the possible consequences for callers and the helpline that might result from careless media coverage.

Media requests for 'case studies' that illustrate a particular trend or phenomenon are always treated with caution at TARSHI. Information about calls that is given to the media is always about generic data, never about specific calls that callers might recognise as being their own. Media representatives sometimes want 'real examples' that would make their media reports stronger, and dangle the carrot of increased and free publicity of our efforts; we respond by explaining that our giving in to their requests would damage callers' trust in the service. Sexuality also being a subject that easily lends itself to sensationalism, we have to be very careful in making sure that journalists understand what we do and why we do it.

Counsellor identity and protection

Just as callers are anonymous, so is the identity of the TARSHI counsellors protected. This is to ensure that boundaries are in place and that the possible abuse of counsellors by crank and obscene callers is kept to a minimum. Code numbers given to callers for identification also serve to identify which counsellor they usually speak to. Counsellors give no personal information about themselves on the helpline. Counsellors are trained to deal firmly but politely with abusive callers. Abusive callers are people who have problems and need help, but this does not merit counsellors having to suffer verbal and emotional violence.

Preventing counsellor burnout is another issue that is part of nurturing well-being of the staff and ensuring that no damage is done to those who provide services.

Comparison of the proposed draft code of ethics with other codes

The proposed Draft Code of ethics (CEHAT) offers broad and general guidelines to those undertaking research or intervention in the field of sexuality. It is a commendable first step in the multi-disciplinary field of sexuality where the intermingling of various disciplines and approaches can often result in confusion for many.

Because the Draft Code has been formulated to address ethical issues that fall within the purview of social science and health research it is comprehensive in its coverage of a range of issues. This necessitates a deeper examination of certain issues of particular relevance to the field of sexuality. As work in this field grows, hopefully there will be greater discussion of ethical dilemmas and their resolution.

Those who work on issues of sexuality might wish to examine Codes of Ethics from other fields and borrow from them to add to what is in the Draft Code. Summarised below with special reference to specific guidelines in the Draft Code, are guidelines from other Codes of Ethics that add to or clarify special points.

Respect and protection of autonomy, rights & dignity of participants (Draft Code: II.4)

The American Sociological Association's (ASA) Code of Ethics states in its General Principle on Respect for People's Rights, Dignity and Diversity, that sociologists strive to " eliminate bias in their professional activities, and they do not tolerate any forms of discrimination based on age; gender; race; ethnicity; national origin; religion; sexual orientation; disability; health conditions; or marital, domestic, or parental status. In all of their work-related activities, sociologists acknowledge the rights of others to hold values, attitudes, and opinions that differ from their own." (Principle D).

This sentiment suits the range of research, counselling and applied activities within the field of sexuality that the Draft Code aims to encompass. The current statement under II.4 is directed specifically at researchers with regard to participants, and includes no specific reference to individual or group values or attitudes that may be particularly relevant within a counselling/NGO context. The ASA principle is of particular relevance while conducting research with marginalised and disadvantaged groups.

Accountability and Transparency (Draft Code: II.7& III.7.2)

The American Political Science Association (APSA) states in its ethical guide aimed at scholars and professors (it is not research-participant centric) that,

> "With regard to any public scholarly activity including publication of research the individual researcher:
> Should disclose all relevant sources of financial support; (5.2)
> Should indicate any condition imposed by financial sponsors or others on research publication, or other scholarly activities. (5.3)
> Scholars have an ethical obligation to make full and complete disclosure of all non-confidential sources involved in their research so that their work can be replicated or tested. (6)"

Section II.7 of the Draft Code (Accountability & Transparency) does not make any specific reference to disclosure of financial support but only "each aspect of the research". Also, Section III.7.2 does not refer to aspects of sponsor conditionality, which might be important keeping in mind that sponsoring agencies might seek to push dubious agendas.

Anonymity (Draft Code: III.4.3 (vi))

The American Anthropological Association (AAA) Statement on Ethics specifies that with regard to anonymity within research, "It should be made clear to informants that anonymity may be compromised unintentionally (1d)". Section III.4.3 of the Draft Code does not explicitly state this possibility which is very real especially while working in community settings where despite the best intentions, there may be no guarantee of protecting anonymity.

Consent (Draft Code: III.4.3 (vii))

This section of the Code states that all informants should be made aware of the possible future use of research or records as secondary data and for unanticipated uses. The University of Wollongong Human Research Ethics Committee (WHREC) Guidelines make the further provision that, "Secondary or subsequent analysis of data beyond that agreed to by participants requires the specific permission of participants (for identifying data)" (p.2).

Participant's Competence (Draft Code: III.4.9)

With regard to the issue of informed consent for individuals who "are rendered incapable or do not have the ability to take a decision" the Draft Code requires that consent be sought from proxies or surrogates, or a process of peer review be undertaken. The WHREC guidelines also include the statement that in such circumstances, "Researchers have a greater responsibility to protect participants from the risks and burdens of research than they would when participants are ordinarily competent adults" (p.2).

Documentation (Draft Code: III.6)

This section is concerned with the ethical use (in terms of confidentiality), of completed research data. However several of the ethical codes reviewed also stress the importance of maintaining adequate data and records for future use. This has relevance for the Draft Code in terms of the work of therapists, counsellors and NGO involved in a wide range of interactions outside of exclusively research-based contexts. The APA Ethics Code (1992) produced by the American Psychological Association (APA) states that, "Psychologists appropriately document their professional and scientific work in order to facilitate provision of services later by them or by other professionals, to ensure accountability, and to meet other requirements of institutions or the law." (1.23a)

Media (Draft Code: III.7.4)

The APA Code also focuses on the responsibility of its members to comply with ethical practices when involved with media presentations in a professional capacity: "When psychologists provide advice or comment by means of public lectures, demonstrations, radio or television programmes, pre-recorded tapes, printed articles, mailed material, or other media, they take responsible precautions to ensure that (1) the statements are based on appropriate psychological literature and practice, (2) the statements are otherwise consistent with this Ethics Code". (3.04) As with the previous section, this would apply both to researchers and to other professionals involved with the range of sexuality-based work.

Role of Peer Reviewers/Referees (Funding) (Draft Code: III.9)

In the WHREC Guidelines for the assessment of research proposals, committee members are asked to consider "What is the relationship between source of funding and the aims of the project? Does that relationship have implications for the ethical conduct of the project, especially the recruitment of participants and the character of information sought?"

The Draft Code does not set out specific points of consideration for Peer Reviewers/Referees. It would seem that an analysis of project funding with regard to ethics could be considered. This immediately brings to mind research concerned with testing particular products, (such as contraceptives or medicines), or new counselling/therapy-based techniques on a particular population, which may be funded by a source with specific developmental or marketing interests.

Institutional Mechanisms (Draft Code: IV)

The Commission to Review the AAA Statements on Ethics (1995) presents an analysis of factors necessary for a body to successfully adjudicate charges of unethical practice. This includes the ability to:
Ensure due process, which involves collection of data, interviews, hearings, etc.
Have the ability to impose meaningful sanctions.
Have moral, if not legal standing.
Be willing and able to take on all appropriate claims.
Be able to deliver what it promises. (B.2,p22)

Because the AAA Statements on Ethics had no legal standing and a weak adjudication mechanism, the Review Commission recommended that the AAA:
direct its energies and resources into establishing an on-going aggressive ethics education programme.
Offer advice to persons who are faced with ethical dilemmas and to persons who are considering bringing a claim of unethical behaviour in another venue.

Since this appears to be very similar to the situation that those working in the social sciences and particularly in the field of sexuality experience, maybe there are some lessons for us here. Of particular interest and applicable in our situation are the recommendations that the Commission made for an educational program in ethics.

> *Recommendations of the AAA Review Commission for an educational program:*
> Produce and periodically update a publication of case studies of ethical dilemmas researchers, teachers and practitioners might face, suitable for use in graduate training, postdoctoral training, and continuing education.

Provide departments technical assistance in establishing educational offerings in ethics.
Conduct ethics training workshops.
Seek a grant....to develop a basic ethics training module, ...which could be supplemented with training specific to the discipline....Develop broad guidelines to help departments determine the appropriate minimum of ethics training which should be offered to different levels of students.

These recommendations are very useful with regard to the Draft Code, and could help in determining its scope and possible routes of expansion in the future.

The AAA Statement on Ethics also states, " Anthropologists may choose to move beyond disseminating research results to a position of advocacy. This is an individual decision, but not an ethical responsibility". (C,2) With reference to the proposed Draft Code, perhaps the Review Committee could be a source of advice (or recommend relevant contacts) for the ethical application/development of advocacy strategies if an individual or group requests this.

References:

American Anthropological Association. (1986). Statements on Ethics.

American Political Science Association (1998). A Guide to Professional Ethics in Political Science.

American Psychological Association (1992). Ethical Principles of Psychologists And Code Of Conduct.

American Sociological Association. ASA Code of Ethics. Approved by ASA Membership in Spring 1997.

Basu, D.P (1994) Appropriate Methodologies for Studying Sexual Behaviour in India. Indian Journal of Social Work: October 1994, LV (4), 573-588.

CEHAT (2000). Ethics in Social Sciences and Health Research: Draft Code of Conduct. CEHAT, Mumbai.

Chandiramani, R. (1996) Rights and Ethics in Interventions, Experiences and Research in the Field of Sexuality. Paper presented at the International Seminar on Advances in Reproductive Health and Sexuality, Mexico City.

Chandiramani, R. (1998) Talking About Sex. Reproductive Health Matters, 12 (6), 76-86.

Commission to Review the American Anthropological Association Statements on Ethics. (1995). Final Report.

Ericksen, J., Steffen, S. (1996) What can we Learn from Sexual Behaviour Surveys: The U.S. Example. In Zeidenstein, S. and Moore, K. (eds.) Learning About Sexuality. The Population Council, New York.

George, A. (1997) Sexual Behaviour and Sexual Negotiation among Poor Women and Men in Mumbai - An Exploratory Study. SAHAJ Society for Health Alternatives, Baroda.

Gostin, L. (1991) Ethical Principles for the Conduct of Human Subject Research: Population-Based Research and Ethics. Law, Medicine and Health Care, 19 (3-4): 191-201.

Gurbaxani, S., Khanna, R. (1999) Review of Research Studies on Sexuality and Sexual Behaviour in India (1990-1999): Overview. WOHTRAC, MS University of Baroda, Vadodara. (Draft for internal circulation)

Holland, J., Ramazanoglu, C., Sharpe, S., & Thomson, R. (1999). Feminist Methodology and Young People's Sexuality in Parker, R. & Aggleton, P. (Eds.) 'Culture, Society & Sexuality' UCL Press, London.

Ingham, R & Memon, A. (1990) Methodological Issues in the Study of Sexual Behaviour in the Context of HIV-Infection - An Overview. Working Paper 90/3. Dept of Psychology, University of Southampton.

Joshi, A., Dhapola, M., Kurian, E., Metha, A., Rajeshwari, M., Biswas, S. (1997) Rural Women's Experiences and Perceptions of Marital Sexual Relationships - a Working Paper. Operations Research Group, Baroda.

Khanna, R. 1996, "Research and Intervention: a Woman-centred Approach". Paper presented at Reconceiving Sexuality: International Perspectives on Gender, Sexuality and Sexual Health. Rio de Janeiro, April 14-17, 1996.

Ringheim, K. (1995) Ethical Issues in Social Science Research with Special Reference to Sexual Behaviour Research. Social Science and Medicine, 40 (12): 1691-1697

Rubin, G. (1999). Thinking Sex: Notes for a Radical Theory of the Politics of Sexuality in Parker, R. & Aggleton, P. (Eds.) 'Culture, Society & Sexuality' UCL Press, London.

Savara, M., Sridhar, C.R. (1994). Sexual Behaviour Amongst Different Occupational Groups in Maharashtra. The Indian Journal of Social Work. LV (4), pp 625.

United Nations (1948). The Universal Declaration of Human Rights.

University of Wollongong Human Research Ethics Committee. (undated). Guidelines for Applicants Seeking Human Research Ethics Committee approval of a Research Project.

Vance, C. 1999. Anthropology Rediscovers Sexuality: A Theoretical Comment in Parker, R. & Aggleton, P. (Eds.) 'Culture, Society & Sexuality' UCL Press, London.

Vohra, S. (1998) Empathy and Sympathy. Psychological Foundations: The Journal. Vol I, December, 1998, pp 53-55.

Radhika Chandiramani is a qualified clinical psychologist who works on issues of sexuality with TARSHI.
Lesley Jane Berry is a student of anthropology at the School of Oriental and African Studies, University of London.
TARSHI, *49 Golf Links, 2nd Floor, New Delhi 110 003, India. E-mail:* tarshi@vsnl.com

BACKGROUND PAPER: 3
Draft Not To Be Quoted

Ethical dilemmas in Health Research with Women

A case study of a survey and a qualitative study

Neha Madhiwalla

Research with women, involves additional dilemmas that arise from their lack of autonomy. Conventionally one conceptualizes there research relationships as that existing between two sets of free agents - researchers and participants, who may, of course have very different levels of control over the research process.

However, researching women inevitably absorbs into the interaction several other players without whose assent, women may not act. This is not to deny that every researcher and participant is entangled in a network of power relations. Funders, the state, employers, landlords, and politicians, among others, inevitably influence and control the direction of scope of the research and guide the actions of the researchers and participants. However, in most of these cases, they influence the direct players as a class. And thus it may be possible to engage with them as a class (participants may collectively ignore a ban imposed by the employer, or on entire village may boycott a survey). In the case of women, however, even in the absence of any overt sign of hostility, each individual woman must negotiate with their individual households, as must the researcher. In a sense, it is implied and understood that women must seek the consent of the households. However, to define intelligent adult women as having gatekeepers even when they are not living in closed institutions, is unthinkable. But in real life, is it not what we always do? Most often, one is caught between legitimizing the authority of men or older women to dictate the actions of women on the one hand and ignoring or resisting their control even at the risk of retaliation on the other.

While the ethical response for the individual researcher in a specific instance may be the former, can we deny it is the second option, which represents the truly ethical stand, which is truer to the commitment that we make to women's empowerment?

Both women participants and researchers are always engaged in a process of building alliances with men. Women will very pointedly involved strategic male members in the research process as a means of protecting themselves from the danger that may be posed by the researchers. Alternately, researchers may approach men and legitimise their authority in order to gain access to women and ensure their safety and also ensure that there will be no disruption or opposition later on. However, having once involved men the situation is not easy for women participants to control it. The research process then involves a continuous process of negotiation and bargaining, in which the women participants are particularly vulnerable. However, for either group, this strategic move foregrounds patriarchal subordination and reinforces the existing power structure.

The lack of autonomy also relates to the setting of priorities in research. In the context of women's health research, another important issue relates to relevance and control over knowledge. Women have suffered as much as they have benefited from social research. On the one hand, perceptive studies have exposed how little women have gained from development and why women and girls continue to suffer poorer health and higher mortality than their menfolk. On the other hand, so much health research has gone into improve acceptance of undemocratic contraception programme and effecting behaviour change among disempowered sex workers and poor mothers. This not to deny that family planning and safe sexual behaviour or more informed childrearing practices are admirable goals. However, these processes are meaningful in a context where women can exercise their free will and do not have to make choices under duress. Thus research which aims to change women without changing their context is not relevant unless it examines the pressures and constraints that may prevent women from acting in ways, beneficial to themselves, even against their better judgement.

Not only are women unable to exercise control over their community, they also have very control over the researchers' knowledge. As a group, women have very limited access to education. Marginalised women are even more disadvantaged. They are isolated not merely because they are poor and uneducated, but also because they are women, unable to travel far from their homes and too intimidated to want to enter an office. Researchers gain legitimacy from the fact that they are able to speak a language that is comprehensible to those in power. They are thus able to speak for women. On the other hand, women do not possess the means of using and understanding the knowledge that have helped produce. Education teaches people how to use this language of knowledge. Those who are deprived the right to education (as most women are) do not have the language to use or understand the knowledge that scientific inquiry produces. It must be debated whether it is not ethical responsibility of the research community to bridge the knowledge gap between the participants and themselves. This issue relates to the politics of research assuredly, but also to the ethics in an indirect way. Many of the areas, which we consider unexplored, are so deemed because there is no written account of them. By gaining access to the written word, not only would the participants be able to judge what is produced on them, but it would also allow them to counter the monopoly of researchers to speak for them. This may very fundamentally alter relationships between researchers, policy makers and the community wherein the imperative to heed the voices of women may become very compelling indeed.

Against this general background, I reflect on two experiences of research conducted while working in a structured research organisation. These experiences illustrate the manner in which ethical dilemmas related to women's research emerged and our attempts to resolve them. The resolution of these problems was not complete, nor ideally accomplished. However, we attempted within our limited capacities to deal with them with some measure of integrity.

I. Household Survey on Women's Health

Apparently, survey research poses fewer ethical questions due to the structured nature of the research methods as well as the interaction between researcher and participants. However, the impersonal nature of the survey itself poses other ethical dilemmas and issues.

In 1996, we conducted a household survey in Nasik district to document illness, utilisation of health care and health expenditure. Although information was collected on all family members, there was a specific focus on women. We therefore, introduced probing (a list of symptoms) in order to record morbidity that is perceived but not reported. The field work team was entirely female, consisting of investigators, young women between 18 and 25 years, research assistants and three researchers. Our investigators were living in Nasik and Bombay and had about 10-12 years of formal education. Their fathers/husbands were largely industrial workers, petty traders or in the lower rungs of the service sector. (office assistants, bus conductors etc).

The survey covered rural areas of Igatpuri taluka and Nasik city. The households were randomly selected from the selected villages and urban clusters. They represented a cross section of the population of the district. In the rural phase, researchers visited the selected villages, established contact with the local leaders and women in the community. We also conducted key informant interviews with women and men in the villages. This initial visit was also used to fix the time and date of the survey. Usually, there was a gap of three or four days between the first visit by the researchers and the arrival of the research team. This time was sufficient for information to spread by word of mouth that such a survey was being planned. In almost all villages, we also held a public meeting for women in the balwadi, samaj mandir or temple to give information about the study, its objectives, the date and the process involved (mapping, sampling, and interview).

This process continued simultaneously with data collection. Thus, while the survey was going on in one village, the researchers would establish contact in the next village. Often, women from one village would have natal homes in the next sampled village. This network of relationships was very useful in reaching out directly to women and households without the mediation of the established leadership (panchayat, health workers, and police patil).

On average, each interview took an hour and a half. This included the time spent by the investigators in introducing themselves and the study. A pamphlet had been prepared stating full details about the organisation, the objectives of the research, the use that the data would be put to and the rights of the participants (to withdraw from the survey, to refuse to answer specific questions and the right to confidentiality) and the names of the individual researcher involved in the study as well as the organisation head (co-ordinator). This pamphlet was signed by the researchers and the co-ordinator and hence, represented a written endorsement of all of the above. This was read out and given to the respondent prior to the interview.

The same process was followed in the urban areas. The only difference being that in the clusters of bungalows and apartment blocks, no community meetings were held. Each household was approached individually.

Issues

Typically, surveys concern communities rather than individuals and hence in this study too, we approached the 'community' before starting the survey. The idea was to obtain *'informed consent'*, not merely from individual respondents,' but from the community. Of course, it is very difficult to define what constitutes the community's consent. We resolved this problem by holding public meetings prior to the survey where in we explained the nature of the survey, its objectives, the method of sampling and the interview. We took care to ensure that at least more than half of the participants in these meetings were women. We also held as many meetings as required. (in different lanes and quarters of the slum/villages, settlements) to ensure the participation of women of all the identifiable groups in that community (including dalits, the different tribal groups, minority communities and migrants) We invited questions in these meeting and clarified doubts. The community meeting was a way of indicating that we recognised the existence of the collective and, apart from individual women, were also accountable to the collective. A meeting is a public space, where women felt more secure in raising doubts and reservations, because they could rely on other women for support. It also indicated that we were willing to face them as a group. If we felt that the group in general, was not convinced or that they had not entirely grasped the information, we held a meeting again after a couple of days just prior to the survey. If we felt that there was unsurmountable opposition to the exercise, we did not conduct the survey in that particular community at all.

Needless to add, the consent of the elected representatives and the local leaders was also sought, not only for ethical reasons, but pragmatic considerations as well. However, at no point, did we use their consent as a proxy for the consent of the actual participants. In two instances, inspite of the exhortations of the sarpanch to conduct the survey, we did not do so because we surmised that the actual respondents did not want it. While we decided that this was the only ethical position that we could take, the other side of our actions must be very clearly understood.

When we tried to examine why did an entire community refused to participate in the survey, we found that in both cases, the women were particularly vulnerable within their own communities.

In one instance, the village was a remote tribal village, facing large scale take over of land by a private investor, where there was seasonal out-migration of men and a noticeably higher incidence of bigamy and, most definitely a marked deprivation in terms of health and object poverty. In the other instance, the village bordered an artillery range and had a very large number of young widows whose husbands had been killed while foraging for scrap metal inside the range. The entire community straddled a precarious balance between observing the law and ensuring survival. It was evident that the women were paying a heavy price for this as well.

Among the other significant issues relating to this research study was the relationship between the main researchers and the investigators. It was understood that unless investigators had internalized the methods of the research and its objectives, they would not be able to do justice to the study. Thus, they were trained rigorously, especially with the intention of making them sensitive to the issue and receptive to women. However, although the training equipped our team intellectually and ideologically, we ourselves had not anticipated the emotional burden that the investigators would have to carry. The survey was a large-scale exercise, involving a large team of twenty people and considerably material resource. The pace of the survey was guided by logistics as well as the imperative to interview all the households within the same season. Thus, as the survey progressed, the pace became more and more punishing as we attempted to make up for unforeseen delays and days lost due to bad weather. Thus, typical to the survey are short sporadic interactions with participants, who have been chosen merely because their house has been randomly sampled. However, the nature of this interaction itself can become particularly distressing.

Each set of two investigators encountered on average four to five households a day and met ten or twelve women. Each day brought its store of traumatic stories of death, suffering and loss. Women broke down and cried and it was not unusual for the investigators to join them. Even the most experienced of our investigators found herself getting involved in the life of the woman she interviewed. As the leaders of the team, however, it was our duty to keep the work moving. Often, we had to goad reluctant investigators out of one house and into the next. The fear was not merely that precious time would be lost, but also that the investigators would spend enormous amounts of physical and emotional energy generating information that we were not capable of using. Our investigators, justifiably, got angry at our attempts to put the research above the natural impulse to listen, console and counsel. The brevity of the contact itself became the source of much distress. The result was sporadic bouts of utter skepticism about the entire exercise and a marked reluctance to continue working in this way. Things were not made easier by the fact that investigators continuously faced questions from participants about was to be gained by this exercise. While they had been trained to explain the long-term objective of gender sensitive research, it is easy to see why they often did not believe their own answers.

A coping mechanism which they (and certainly we ourselves) developed was a feeling of being anaesthetised. Also, after the third or fourth week of field-work, all the stories sounded vaguely familiar. Therefore, it was very necessary to evolve a more creative way of coping with this situation. A way out that would allow us to continue working without feeling burnt out, but still prevent us from becoming mechanical and our response synthetic.

We therefore institutionalised the evening team meeting. It was held in any place that was private, mostly at our headquarters in Nasik, or in the jeep and a restaurant on the way back. The meeting was held to take stock of the work accomplished and the problems encountered. The investigators typically spent hours relating what various women had told them and what they had experienced themselves. The meetings were cathartic. They helped all of us to release the pent up frustrations and articulate our sense of anger and helplessness. We realised how important it was for even the most junior member of the research team to be able to distance herself from the issue and view it within a perspective. All of us also brought our share of personal problems and experiences that made the field-work even more difficult, This space was used to resolve those issues. Typically, the meetings were never entirely professional, but involved a lot of personal sharing of physical contact, of expressions of concern and affection and annoyance and irritation as well. It is largely on account of these meetings that we were able to complete the survey successfully and divert some of our frustration creatively into writing of field-notes and diaries (which all of us did).

Apart from the ethical issue of exposing the juniors in the team to experiences that they may not have been prepared for, the larger issue relates to the relationship of the researchers itself. It is difficult to argue against the existence of a hierarchy in the research team itself. One recognises that there is need to reiterate that researchers have different roles. However, it is still important to question why certain ways of writing legitimise research more than others. This is particularly relevant in the field of women's research where qualitative techniques are used extensively and very sensitive issues are probed in detail. The depth and richness of the data itself lends much to the quality of the research and, thus, investigators and assistants who conduct the actual interviews and group discussions in many cases are very important players. Their sensitivity, understanding of the issue and a high level of skill are pre-conditions for good data collection. Not only do are they involved intensively in this phase of the research, a participatory mode of functioning may actually equip them with additional skills. Our own experiences indicated that the meetings and discussions imparted certain skills to investigators that are normally associated with research writing. They learnt how to abstract and how to generalise and how to analyse situations from what we would understand as a 'sociological' point of view. Their skills of writing were admittedly poor because the level of education was generally quite low. However, these are skills that can be acquired with effort and inputs. While our investigators may have been too junior and ill –equipped to manage all the phases of research, it is quite possible that investigators who have much more formal education and some training may become capable of doing research independently and quite competently. It is important that designation does not define roles and space is created for junior members to share in the writing. However, are our institutions open enough to absorb people who may raise themselves from below? This issue is quite distinct from sharing research with participants, as is the norm in 'participatory research' where they have a say in designing the methodology and the conduct of the research as well as in the use of it.

While participants share the gains of the research largely through changes, which result in the community after the research (by an improvement in the PDS for e.g.), junior researchers would share the professional gains and prestige associated with research. It would involve changing the policies of institutions and implement measures that seriously challenge the existing hierarchies in institutions. The material gains too would be distributed and serious questions would be posed about the social structure of research organisations and the class structure that they reflect.

II. Qualitative study of changes in the living environment of women living in an industrial slum in Bombay.

The ethics of research in qualitative studies poses contrasting challenges. In general, the interaction with participants is of longer duration and more intense. Qualitative data collection also tends to isolate researcher and participant because of the nature of the inquiry. Thus, the issues revolve around sustaining relationships, terminating them meaningfully and coping with the intensely personal nature of the exercise. It becomes important for the researcher to be able to step back from the individual experience and view it from a more objective point of view.

In the second study, we used extensively, the in depth interview. Fortunately, for us, broaching the subject and openly selecting women for interviews was not problematic. The objective of the study was to document changes occurring in the living environment of women on account on changes in the economy, which affected their work, employment and access to services. We were also interested in establishing links between these changes and women's health situation. The study was based largely on in–depth interviews with 40 women. The method for selecting these women was a matrix of five variables age, marital status, work-status, duration of stay and community. We selected two slum settlements and obtained this information for a large number of women and classified women into this matrix. Following this, we selected two participants from each cell of the matrix.

Issues

As we were largely concerned with issues of livelihood and work, it was not difficult to gain the consent of the participants of the study. The fact that our sampling design was also quite straightforward and the selection of the participants was based on very commonly known details –there was no difficulty in explaining why some women were chosen among the many. However, protecting the privacy of the selected participants and their confidentiality was still problematic. Most problematic was gaining the consent of the minor girls (14-18 years) and interviewing them in such a way that they were not stigmatised. We were interested in including adolescent girls because we were convinced that their domestic roles were very similar to adult women and they shared similar problems, which was never acknowledged. Nonetheless, the selection of these girls, who in the general understanding, did not really qualify as women aroused a lot of curiosity and suspicion. Inspite of allowing us to interview them, there was a hint of reluctance from their families itself, who feared that these girls might complain about them or speak ill of them. Invariably, their mothers or others in the household would want to know what they said. The girls themselves were very edgy about speaking to us in the community, especially in the presence of their family members. We were caught in a double bind. On the one hand, we wanted to interview them in full view of the community, in order to assure them of the innocuousness of the exercise, on the other, the girls wanted to speak in place where no one could hear them or see. However this was difficult physically because the girls hardly ever went out of the community on their own, unescorted. We tried to strike a balance between the two and made sure that the girls' privacy and confidentiality was never violated, even as we ensured that we did not arouse unnecessary suspicion.

A very important issue that this study brought to the fore was that of identity. It is common practice in research and development work to look for people who share some cultural ties with the community where we intend to work. While knowing the language and the customs of the group/community does resolve certain practical difficulties, there is also a certain intangible gain from the psychological feeling of comfort that participants derive from interacting with an 'insider'. To establish this insider status, it is never necessary to overtly announce one's caste, religious or linguistic background. In a complex social context as in Mumbai, most people are adept at guessing these from the smallest signs in the name, dress and speech. Sometimes, However, these signs can be misleading.

My name and appearance does not immediately suggest to people that I am Hindu, which is the religion into which I was born. Because I happen to be Gujarati speaking, (not a community with which this particular group is very familiar) it is all the more difficult to guess whether I am Hindu. As it was assumed that I do not look like a Hindu, it was decided that I must be Muslim. The first indication that I received that the Muslim households in the community may have misread my origins came when people would say, for e.g. so and so belongs to our kind (apni jat). As we progressed further, I realised that this perception may be more widespread than I had imagined. By the time, I began to clarify that I was not Muslim, a certain trust had already been built. It no longer mattered to people that I was not a co-religionist. This episode involves not so much ethical issues as political ones. While one may consciously deceive participants by 'claiming' to be something, which one is not, this was certainly not such a case. However, the fact that people immediately want to place you in a grid of social identities, is well known to us. The fact that it contributes, even if only sub-consciously, to the building of relationships is also something we all acknowledge. Our religious identity may not be important to ourselves, but it works in very subtle ways to draw people towards us and away from us too.

It is clearly unethical to manipulate identities, especially those that we ourselves do not acknowledge (even though they may not be false), for the purpose of research. Often, participants are led to believe that they may share certain interests or certain histories in common and they react accordingly. For those of us, who can clearly shift identities easily, it is tempting indeed to do so in order to make every participant feel that they are speaking with an insider. One is always emphasising certain identities, while obscuring others. Thus, being a woman is more relevant that being Hindu. Our ideological positions are not much more than the prioritisation of these identities. While they may all co-exist, what I value must be fore-grounded. It is equally important to state our ideological stance, at least, on relevant issues, as it is to brief participants about the objectives of our study. Especially when we study political affiliations, social prejudices and other such issues, it is our responsibility not to keep the participants in doubt about our own beliefs. No doubt, this problem can be fairly complicated in the instances where we are ideologically opposed to the participants and the interests they represent.

Another issue which dogs studies done with very specific individuals or distinct communities is the matter of revealing names and leaving markers in the text that makes it possible to identify the individuals involved in the study. One has to strike a balance between maintaining anonymity and yet making the context of the study clear. This is a problem that we confronted in our study. As the focus of the study was the living environment, identifying the exact locations of the settlements lent a strong sense of credibility. However, it also made the communities identifiable, especially to those who are familiar with the area. This problem was particularly important to resolve because we were committed to return findings of the study to the participants. When we started preparing the report in the vernacular, we realised that let alone names, even details of the women's narratives could not be included. Initially, we had a plan to develop fictitious narratives, but we soon realised that even that would lead to misunderstanding. Secondly, some of the findings of the study clearly indict the community's own actions as being responsible for its problems. Most of these relate to the hierarchical nature of the community leadership and their role in perpetuating the subordination of women. While it would be honest, in some form, to return even these findings to the community, it would be irresponsible to do so merely by disseminating the report. Do we have the right to sit I judgement of people's intentions and actions, when we do not wish to share their predicament and work with them towards resolving their problems? This, inexorably, draws us towards the realm of activism or, at least, intervention. While, it is undeniable that research should ultimately lead to progressive action, how feasible is it for individual researchers or teams to get involved in a process of this kind.

We ourselves have still not resolved this dilemma. However, there seems to be a clear indication that returning findings to this community will involve a prolonged and gradual process of discussion, debate and self-reflection. While we hardly endeavour to instruct the community, we can be quite certain that such a process will throw up insights that we may have missed earlier and a better understanding of the limitations and predilections of either party will be revealed.

Conclusion

In the previous sections, I have outlined the nature of ethical dilemmas that we confronted while conducting these two studies. While some of these issues are gender specific, some are of a general nature. The teams involved resolved the ethical dilemmas by responding to problems, as they arose evolving a consensus through discussion and self-reflection. The utility of an ethics guideline would largely lie in pre-empting these problems and allowing researchers to devise strategies with the compulsion imposed by the being in the midst of an unfinished process that can neither be reversed nor stopped.

The guidelines would also facilitate discussion between different team members who may not share a similar perspective. The guideline also represents the basic minimum, which each strategy must adhere to and beyond which compromise is not acceptable.

It is however, necessary to contextualise these guidelines where research with women in concerned. The universal principles apply, but the specific indicators may be difficult to identify. Just as in any other field, it is difficult and, at the same time, imperative to separate the interest of women from that of the household/community.

Thus do we define consent of the household as consent of the woman? Does gain accruing to the household amount to gain accrued to the woman. Is sharing the knowledge with the community in a written form in front of the elders and community leaders enough? What will women do with knowledge that they are not empowered to use? What stand should we take when women try to set up a system of checks and balances between the researcher and the authority figures, who are conventionally bound to protect her. By accepting their legitimacy, one automatically endorses their right to share the knowledge resulting from the research. Does this compromise our commitment towards women who are the rightful recipients of that knowledge. How does one then confront the same authority figures?

Finally, one must address the problems within? An important agenda for women's studies has been widening the definition of knowledge and challenging the norms governing the hierarchy of knowledge. There is an assertion of the legitimacy of women's voices, oral cultures and lay knowledge. However, as women's studies get recognised and institutionalised, new hierarchies are being established in new institutions. Research in women's issues, especially women's health is not confined to activist groups and dissidents among the academic community. Apart from the state, which continues to conduct research *on* women, it involves large research institutions in the mainstream, large non-governmental organisations and multi-lateral agencies, many of whom claim to be conducting research *with* women. All these agencies are spread across a wide ideological and political spectrum. Nonetheless, is it sufficient to claim that women participants are partners? What about the woman research investigator (who also forms the informal sector of the research industry, indispensable and yet highly substitutable), who should legitimately share the direct gains of research, both material and social?

(This paper draws on the experiences of two research studies conducted while I was working at CEHAT. I would like to acknowledge the contribution of my team members to the discussions that led to the writing of this paper. In particular, I would like to acknowledge Rupashri Sinha and Padma Deosthali, with whom I not only discussed but also lived these experiences and to whom much of the credit for this paper should legitimately go. However the views expressed in this paper are mine only.)

Ms. Neha Madhiwalla
Author is health researcher and activist.
She has worked at CEHAT till recently.
Editor, "*Medico Friend Circle Bulletin*" (From July 2000)

ETHICS AND EPIDEMIOLOGICAL RESEARCH

SOME DILEMMAS AND DIFFICULTIES IN THE INDIAN MILIEU

Madhukar Pai

With the intense heat generated over the placebo controlled HIV perinatal trials, the ethics of health research are being debated world over. The Indian government (Mudur 1997) and the media (New Indian Express 2000) have also voiced concern that the Third World might be "reduced to one big lab" for human experimentation by western researchers. In this context, the draft code of conduct for Ethics in Social Sciences and Health Research (EPW 2000) is a welcome development and could greatly contribute to the debate within India.

Historically, the Nuremberg Code was one of the earliest ethical guides on research involving human subjects. The World Medical Association Declaration of Helsinki, the Belmont Report, the Council on International Organizations for Medical Sciences (CIOMS) International Guidelines, and the WHO Guidelines for Good Clinical Practice for Trials on Pharmaceutical Products are examples of documents for ethical review and conduct of research. In India, the Indian Council for Medical Research (ICMR) is finalising a Draft Consultative Document on Ethical Guidelines on Biomedical Research Involving Human Subjects (ICMR 1997). Despite the plethora of guidelines, problems remain. In this review, I will not attempt to discuss these well known guidelines. Instead, I will discuss some ethical dilemmas and difficulties that I have encountered in my career as a researcher and a research adviser.

Is bad science ethical?

According to the CIOMS guidelines, "a study that is scientifically unsound is unethical in exposing subjects to risk or inconvenience and achieving no benefit in knowledge." (CIOMS, 1991). Bad science, therefore, is considered unethical. Altman (Altman 1982) summarised the ethical implications of poorly conducted research:

> "The misuse of patients by exposing them to unjustified risk and inconvenience;
> The misuse of resources, including the researchers' time, which could be better employed on more valuable activities; and
> The consequences of publishing misleading results, which may include carrying out of unnecessary further work."

Altman, in an editorial called *"The scandal of poor medical research"* also wrote, "Doctors need not be experts in statistics, but they should understand the principles of sound methods of research. If they can also analyse their own data, so much the better. Amazingly, it is widely considered acceptable for medical researchers to be ignorant of statistics." Altman goes on to discuss what he calls the "scandal" of poor medical research. He asks, "What should we think about a doctor who uses the wrong treatment, either willfully or through ignorance, or who uses the right treatment wrongly? Most people would agree that such behaviour was unprofessional, arguably unethical, and certainly unacceptable. What, then, should we think about researchers who use the wrong techniques (either willfully or in ignorance), use the right techniques wrongly, misinterpret their results, report their results selectively, cite the literature selectively, and draw unjustified conclusions? We should be appalled. Yet numerous studies of the medical literature...have shown that all of the above phenomena are common. This is surely a scandal."

In India, we have people doing medical research without adequate training or understanding of research methodology. This particularly true of medical professionals. Most doctors have a deep sense of fear of epidemiology and statistics. Even reading original journal articles is a daunting task for them. Deplorably, most doctors graduate with absolutely no concept of even elementary epidemiology and biostatistics. These are grossly neglected areas of medical education. (Rajagopalan 1997). Given this scenario, it does not come as a surprise that there is a paucity of good quality medical research and only a few Indian journals are indexed and of good quality (Reddy et al. 1991, Nundy 1998). Many Indian papers go unnoticed and have a very small impact on the global scene (Arunachalam 1997). Much of the Indian medical research is largely irrelevant to the health problems of the country (Arunachalam 1997). Another survey demonstrated that there are many medical colleges in India which do not contribute even one peer reviewed publication in a year (Arora et al. 1996).

Bad science, we know, can be particularly dangerous in experimental studies. On the one hand, it may be unethical to introduce into general use a therapy or drug which is totally untested or poorly tested. As Sir Austin Bradford Hill put it "The ethical problem is, indeed, not solely one of human experimentation; it can also be one of *refraining from human experimentation.*" (Hill 1991; emphasis added). On the other hand, a clinical trial should not be undertaken when, because of the absence of randomization, blinding, or sufficient number of subjects, it is unlikely to provide a conclusive answer (Hulley 1988). Indeed, it is important that a researcher embarking on a clinical trial make every effort to design the trial well and pay attention to all the core issues in the trial. It is quite common to see reports concluding that no inference could be made about the efficacy of the new treatment because of inadequate sample size. Why put human lives at risk, and spend a lot of resources when the research question is unlikely to be satisfactorily answered?

In fact, apart from protecting patients from risk, one of the important functions of an Institutional Review Board (IRB) is to safeguard against useless studies, which are unethical. In the words of May (May 1975), "A poorly designed or poorly conceived experiment is unethical by definition and should not be permitted. Further it is the responsibility of the review committee to ensure that the conception and design meet the accepted canons of scientific method because we are dealing with experimentation which may not be for the individual subject's direct benefit."

Poorly done research will continue to be a major problem in India until we ensure that young researchers get adequate grounding in basic research methodology. Those who supervise research also need these inputs. Training of faculty and guides would thus be an important task to ensure better quality research in India.

Forced research and disinterested researchers

The draft code of conduct for Ethics in Social Sciences and Health Research (EPW 2000) states "...every researcher must acquire adequate knowledge and ability, and should have commitment to do research." What are the ethical implications of research done by those who are totally disinterested in doing research?

Most universities in India, the Medical Council of India, and the National Board of Examinations include postgraduate dissertations as mandatory requirements for completion of postgraduate degree programs. Thus, all medical postgraduates are required to do research for the sake of completing their training. It is a well known fact that many postgraduates are disinterested in doing research and dissertations are usually put together one month before the examinations. There is concern that plagiarism, fabrication, and "recycling" of old dissertations is common (Gitanjali et al. 1998). Needless to say, because dissertations are mediocre they hardly get published in journals subsequently. Indeed, some authors have raised the question whether this practice of submitting dissertations serves any meaningful purpose (Gitanjali et al. 1998).

Good research requires interest and commitment. This might be lacking among many postgraduates. Given a choice, many postgraduates would probably choose not to do any research. By forcing them to do research, are we fostering an ideal environment for poor quality (unethical) research? The problem, partly, is also the dearth of good research advisors and guides in our milieu.

I have had the opportunity to guide several interns and postgraduates in their research work and have encountered many students who were completely disinterested in research. Because they had to do some research for completing training, these students would often sham work and end up with very mediocre work. In one case, I actually discovered two of my students fabricating the entire research work. Since I had never encountered something like, I took this up to a senior faculty member. Not wishing to jeopardize their careers, we decided to warn them and make them repeat the entire study. This anecdote only illustrates the apathy that occurs when people are forced into doing research.

The solution to this problem obviously lies in improving the quality of medical education in India, better teaching of research methodology at the undergraduate and postgraduate level, training of guides and teachers, increasing resources for research (funds, facilities, etc.) and recognition and rewarding of researchers for their contribution. Ultimately, students must begin to perceive research as an activity which is inherently interesting and rewarding. When that happens, the learning objective behind dissertations will be fulfilled.

Research involving the pharmaceutical industry

Drug companies are normally required to perform clinical trials for getting approval from the Drug Controller of India for marketing new drugs. Many drug companies approach private hospitals and doctors for undertaking their trials. Usually, they offer financial inducements to the hospitals for taking on their trials. There have been reports of doctors getting paid huge sums of money for recruiting patients into trials (Eichenwald, et al. 1999a). Clinicians have been found guilty of coercing patients into trials without adequate informed consent (Eichenwald et al. 1999b). The involvement of physicians in drug trials has raised concern whether the dual role of physician-researcher is a conflict of interest because the objectives of research and patient-care might differ a great deal (Levine 1992, Miller et al. 1998). This dilemma was brought out sensitively in *Miss Evers' Boys*, a superb movie on the infamous Tuskegee study. In this study, black American males with syphilis were denied penicillin for many years to study the natural history of the disease. In the movie, Miss Evers is a black nurse who takes care of these patients with syphilis. On the one hand, she believes in the importance of the scientific study (which, she is told, is "for the greater good of the community"), while on the other hand, she is desperate to provide her ailing patients with penicillin (which she knows is very effective). Levine calls physician-researchers 'double agents' and suggests that whenever one individual attempts to play both roles simultaneously, as is often seen in clinical trials of new therapies, the role of the IRB becomes very crucial for protecting the interests of the patients (Levine 1992).

One of the problems with industry sponsored trials in India is that many of them are done on very small samples which just do not have adequate statistical power (sample size) to pick up a genuine treatment effects even if they exist. This, by itself, could be considered unethical because an under-powered study would not be able to answer the research question conclusively. Also, the hospitals which agree to do these trials often have little control over the study design – the protocols are prepared by the companies and hospitals are expected to adhere to them. The data is usually 'owned' by the drug companies and sometimes they may not publish the data at all. Their purpose, after all, is just to get approval for marketing from the Drug Controller. Also, drug companies have been caught suppressing findings which are not favorable to their products. The Synthroid scandal highlights this issue forcefully (Drummond 1997). Boots, a drug company which manufactures Synthroid, a synthetic thryoxine, waged a forceful campaign to discredit a study which showed that Synthroid was no better than other natural thyroxine preparations. Boots had originally sponsored this study, but when the results were not in favour of their product, it tried its best to prevent it from getting published. A JAMA editorial on this warned that "scientists should never sign any agreement that give their sponsors veto power over publication." (Drummond 1997). The draft code of conduct for Ethics in Social Sciences and Health Research (EPW 2000) also echoes this concern. In our hospital, my colleagues and I have had offers to get involved with such drug company sponsored and designed research. In all these situations, the research committee of my institution debated on the issue, and, as an institution we decided against accepting such offers.

Authorship and ethics of publishing

Authorship of papers is a very problematic issue in our country (Jesani 1996). Few researchers have clarity about how authorship should be granted and how the sequence of authors should be decided. Authorship is hardly discussed and debated among all those involved in research. It is usually decided unilaterally by the senior person or the principal investigator. Junior researchers often do not have the authority or willpower to question authorship and author sequencing. The practice of including the name of the senior faculty member/head of the department is all too common. "Gift coauthorships" are also common (Engler et al. 1987). This is particularly common in research labs where the head of the lab or the person who provides some research facility gets authorship even if he/she was never involved in the research at all. In my experience, I have rarely come across senior faculty members who told me to exclude their names from papers because they have not contributed sufficiently to the work. Sometimes this phenomenon works in the reverse. I have heard of instances where excellent studies have never been published or publication delayed for years because of serious fights among researchers over who should be the first author.

Ethics of not publishing enough

I wish we had some data on what proportion of the research work in India gets published. I would imagine a small proportion. There have been discussions on the low output of publications from India (Nundy 1998, Pandya 1990, Reddy 1991). In our environment, it is not uncommon for researchers not to publish their work. Research work, thus, does not enter the public domain. As a culture, we are not very aggressive about publishing. This is partly because promotions and career advancements are not usually made on the basis of number of publications. While it is probably good not to publish poor quality studies, it is sad that quite a good number of well done research studies are often left unpublished because of laziness and a general laid back attitude towards publishing. It could also be that papers don't get published because our researchers lack knowledge and guidance in how to write scientific papers. Fear of rejection and low self esteem of researchers may be another issue. It is also a widespread practice not to publish or present negative studies. Also, busy clinicians may not have the time to write up their research. Thus, not publishing enough has to be understood in the context of our wider problem of lack of resources for research, poor leadership, lack of encouragement and good guidance.

There are reports on secrecy in medical research (Rosenberg 1996, Drummond 1997) and as Drummond writes, "a major problem in medicine is failure to publish the results of studies that show no advantage to the intervention under study, so that treatments tend to based on biases in favor of the new." Secrecy to protect financial interests and to get ahead of competitors should be distinguished from failure to publish out of laziness.

Whatever the reasons, the ethics of not publishing enough is an important issue in India. Organising workshops on how to write journal articles might help. Journals like the *National Medical Journal of India* have attempted to do this. More such efforts are needed to ensure that good Indian research gets published.

Issues in international research

International health research is increasingly becoming common and many institutions in India now collaborate with foreign institutions. This is partly because foreign researchers find it much easier to get population based data in India than in their own countries. Also, Indian researchers get technical inputs and funding from their western counterparts. While international collaboration is important and can be productive, it brings with it some unique problems. Probably the most important is the fundamental dilemma whether ethical standards should be the same everywhere (ethical universalism) or is it inevitable that they differ from place to place depending on local culture, beliefs and socioeconomic conditions (ethical pluralism). This debate is relevant to all aspects of research and the HIV perinatal trials have accentuated this dilemma. The controversy surrounding HIV trials is worth recollecting in this context.

One of the main problems with the HIV epidemic is the potential for mother to child transmission. In 1994, a study using the drug AZT clearly showed that if AZT is given to the mother during pregnancy and to the newborn, HIV transmission could be greatly reduced. The findings were so impressive that the US Public Health Service recommended that all pregnant women with HIV should receive this regimen as the standard of care. Unfortunately, this drug regimen (called ACTG 076) is very long and expensive. Several clinical trials were then launched in developing countries (funded by agencies like CDC, UNAIDS and NIH) to test efficacy of shorter regimens. However, shorter regimens were not compared against the 076 regimens; instead they were compared against placebo groups (women in this group did not get AZT at all).

Can a placebo arm be justified in a clinical trial when there is an effective therapy already available? It is generally accepted that it is unethical to do a placebo controlled study when some therapy is already existent. No patient should be denied some form of therapy even if it is not very effective.

Controversy erupted when a paper (Lurie & Wolfe 1997) titled "Unethical trials of interventions to reduce perinatal transmission of the human immunodeficiency virus in developing countries" was published in the prestigious *New England Journal of Medicine* with a supporting editorial (Angell 1997). These critics charged that since AZT was shown to be effective in reducing the mother to child transmission, no pregnant woman with HIV should be denied AZT in any trial. Giving placebos to one half of the study participants is unethical, they claimed. They also claimed that these trials were all being done in developing countries and none of them would have passed ethical scrutiny in the developed countries. Since ethical standards should be universal, these trials should have never been allowed in the developing countries, they argued. They also made a plea that "residents of impoverished, postcolonial countries, the majority of whom are people of color, must be protected from potential exploitation in research." (Lurie & Wolfe 1997). Marcia Angell echoed these sentiments by writing that "...the Declaration of Helsinki requires control groups to receive the "best" current treatment, not the local one. The shift in wording between "best" and "local" may be slight, but the implications are profound. Acceptance of this ethical relativism could result in widespread exploitation of vulnerable Third World populations for research programs that could not be carried out in the sponsoring country." (Angell 1997).

In their defense, those (Varmus & Satcher 1997) involved the placebo controlled trials made a plea for understanding the local realities of doing research in developing countries. In these countries, standard of care is vastly different from what exists in developed countries. In most developing countries, women do not get AZT during pregnancy. Also, these studies address an urgent need in the countries where they are being conducted. Shorter and less expensive regimens of AZT could bring it within the reach of many poor countries. They argued that placebo-controlled trials offer more definitive answers about the safety and value of interventions in the setting in which the trials are performed. Other researchers have also opined that, "at the very least, the highest standard of care practically attainable in the host country should be provided to all the study participants. There is no obligation to provide study participants with the highest standard of care attainable elsewhere in the world." (Perinatal HIV Intervention Research in Developing Countries Workshop Participants, 1999).

Subsequent to these debates, the discussion on ethical universalism Vs pluralism continues. Researchers from developing countries have voiced concern that western ethical standards are being imposed on them by people who lack the insight into problems and constraints that exists in developing countries. Guidelines like the Nuremberg Code and Helsinki declaration are now considered western constructs. The CIOMS guidelines come closer to global validity than its predecessors (Levine 1986). Countries like South Africa and Uganda are already drafting ethical guidelines for their own use (Loue et al 1996). The question then is, should each country draft its own ethical guidelines? Is this feasible or desirable? If each country were to do this, would that not be the ultimate victory for the ethical pluralism theory?

Most ethical guidelines are vague on this universalism Vs pluralism problem and the draft code of conduct for Ethics in Social Sciences and Health Research (EPW 2000) states "framing of research questions and agendas should be issue/subject specific and sensitive to the culture or community being studied." This still does not give enough guidance on resolution of this dilemma. In fact, none of the accepted guidelines really address this issue satisfactorily. As Levine states, "an inevitable feature of any document that aspires to global validity is that the fundamental principles must be stated at such a level of abstraction that they do not seem to prescribe or proscribe very many behaviors."

Turning to less philosophical issues, authorship of papers which arise out of international collaborations is a problem. It is quite common to see a foreign researcher as the first author though the study idea might have emerged from India and all the field work and data analysis might have been done in India. Indian researchers in such situations may not always voice their opinion lest foreign funding and support dries up.

The other issue is one of an intense pressure to publish. It is so easy to see the pressure foreign investigators are under to be productive in terms of publishing. They have to be aggressive about publishing in order to survive. This is often reflected in the way they put pressure on our researchers to quickly publish. Even if the paper is not of very good quality, the pressure to publish is very evident. Ownership of data is another issue. In biomedical research, it is common for human lab samples to be sent to western countries for analysis. This is done because we simply do not have the technology to perform sophisticated tests. Once the samples are sent to foreign investigators, who owns the data? I have come across instances where complex molecular level work is done on such samples and the data published without any of the Indian researchers as co-authors.

Ethical Review Boards: concerns and issues

Not all hospitals in India which do research might have ERBs or IRBs (Pandya 1998). ERBs which do exist often encounter some difficult problems (Pandya 1996, Alberti 1995). Those who form a part of the ERB often have limited training in bioethics and the formal steps involved in ethical and scientific review of proposals. They may also lack the background necessary to identify flaws in study design.

I have been a part of an ERB in a hospital which is involved in many clinical trials. While this ERB has a few lay people as a part of the Board, I have often noticed them struggling to understand the technical issues which are inherent in clinical trials (complex study designs, pharmacological information, side effects, molecular and genetic studies, sample size estimation, etc.). Lay people might have genuine difficulties in understanding all the technical details. In such situations, I have noticed a reluctance on their part to question and clarify. Researchers also do not put in enough effort to simplify the technical information for the lay people and clinical trials get approved without much debate. Such problems have been recognised and have led to educational programs for IRB members in the USA (Kefalides 2000). In India, we need more IRBs and training for those who are a part of IRBs.

Field practice areas for teaching research methodology

I have seen many large institutions in our country designating specific geographical areas as "field practice" areas. Students and researchers often work in the same area and repeatedly use the setting for their field work. I have worked in institutions which do this. These institutions also offer medical services to these communities. This, in a way, justifies designating the community for "field practice" and for training students in community health work and research methodology. I have noticed community members getting visibly irritated when students repeatedly visited their homes. But I have also noticed a certain tolerance for such intrusions because of the medical services that are provided by the institution.

The issue is complex. On the one hand, it might be unethical to go back to the same community repeatedly for research purposes (EPW 2000); on the other hand it is also important to expose health workers to field realities and community based research and health work. Also, long term follow up studies of communities have lead to excellent data that has tremendously enhanced evidence based medical practice. The Framingham Heart Study has completed 50 years (Messerli & Mittler 1998) of research in the same community and is widely accepted as one of the finest epidemiological studies ever done.

Occupational health research: conflict of interest

Conflict of interest is a major problem in occupation epidemiology. Occupational health research almost always is undertaken after the approval of the industry or employer. Because of this, researchers often feel that they are obligated to report their study findings to the employer rather than the workers. Needless to say, studies which reveal hazards related to work or poor worker health status never get published. In this process, occupational diseases which ought to be reported (for compensation purposes) never get reported. Workers rarely derive direct benefit from such studies.

How do researchers ensure that they retain the right to publish occupational health data? If they made this clear before the study, they might never get to do the study in the first place! What if the industry demanded confidentiality of the data? Whose rights should be given more importance: the employer or the employee?

Conclusions

To improve ethics in our research, we certainly need to address issues like ethical review, informed consent, IRB, code of conduct, etc. These issues need to be openly discussed and debated by all those who are involved in research. Better awareness, by itself, will help. Education of our researchers in bioethics and ensuring that IRBs clear research projects would also strengthen our research. While these changes might ensure better ethical standards in our research, we might still have to contend with bad science. We thus need to also focus on the quality of scientific studies. Improving the science in our research requires better medical education, better training in research methodology (for both students and faculty), more resources for research, and encouragement and recognition of good research work.

References:

Alberti KGMM. Local research ethics committees. BMJ 1995; 311: 639-641.

Altman D. Misuse of statistics in unethical. In: Statistics in Practice. BMJ, 1982.

Altman D. The scandal of poor medical research. BMJ 1994;308:283-284.

Angell M. The ethics of clinical research in the Third World. NEJM 1997;337:847-849.

Arora M, Banerjee JK, Sahni P, Pande GK, Nundy S. Which are the best undergraduate medical colleges in India. Natl Med J India 1996;9(3):135-140.

Arunachalam S. How relevant is medical research done in India? A study based on Medline. Current Science 1997:72:912-922.

CIOMS. International Guidelines for Ethical Review of Epidemiological Studies, Geneva, 1991.

Drummond R.Thyroid Storm. JAMA 1997;277:1238-1243.

Eichenwald K, Kolata G. A doctor's drug studies turn into fraud. The New York Times, May 17, 1999.

Eichenwald K, Kolata G. Drug trials hide conflicts for doctors. The New York Times, May 16, 1999.

Engler RL, Covell JW, Friedman PJ, Kitcher PS, Peters RM. Misrepresentation and responsibility in medical research. N Engl J Med 1987;317:1383-1389.

Ethics in Social Sciences and Health Research. Economic & Political Weekly 2000: February 19-26.

Gitanjali B, Raveendran R. Teaching research methodology to postgraduates: is dissertation the only method? Natl Med J India. 1998 Jan-Feb;11(1):23-5.

Hill AB, Hill ID. Bradford Hill's Principles of Medical Statistics. 12th Edition. BI Publications, 1991.

Hulley SB et al. Designing Clinical Research. Baltimore: Williams & Wilkins, 1988.

Indian Council for Medical Research (ICMR). Draft Consultantive Document on Ethical Guidelines on Biomedical Research Involving Human Subjects. New Delhi, 1997.

Jesani A. Ethics of authorship. Issues in Medical Ethics 1996;4(4):127.

Kefalides PT. Research on humans faces scrutiny: new policies adopted. Ann Int Med, 21 March, 2000.

Levine RJ. Ethics and regulation of clinical research. 2nd Edition. Urban & Schwarzenberg, Baltimore: 1986.

Levine RJ. Clinical trials and physicians as double agents. Yale J of Biol Med 1992;65:65-74.

Loue S, Okello D, Kawuma M. Research bioethics in the Ugandan context: a program summary. Journal of Law, Medicine & Ethics 1996;24:47-53.

Lurie P, Wolfe SM. Unethical trials of interventions to reduce perinatal transmission of the HIV in developing countries. NEJM 1997;337:847-849.

May WW. The composition and function of ethical committees. J Med Ethics 1975;1:23-29.

Messerli FH, Mittler BS. Framingham at 50. Lancet 1998;352:1006.

Miller FG, Rosenstein DL, DeRenzo EG. Professional integrity in clinical research. JAMA 1998;280:1449-1454.

Miller FG, Rosenstein DL, DeRenzo EG. Professional integrity in clinical research. JAMA 1998;280:1449-54.

Mudur G. India to control foreign research involving Indian patients. BMJ 1997;314:165.
New Indian Express . Editorial. Virus seekers. The Third World cannot be reduced to one big lab. New Indian Express, 26 April, 2000.

Nundy S. What can be done about Indian medical research? Natl Med J India 1998;11(1):1-2.

Pandya S. Why is the output of medical research from India so low? BMJ 1990;301:333.

Pandya SK. Hospital ethics committee. Issues in Medical Ethics 1996;4(2):51-53.

Pandya SK. Organizing a public debate: ethical guidelines on biomedical research in humans. Natl Med J India 1998;11(6):294-96.

Perinatal HIV Intervention Research in Developing Countries Workshop Participants. Science, ethics, and the future of research into maternal infant transmission of HIV-1. Lancet 1999;353:832-36.

Rajagopalan A. Medical research in India. Current Science 1997;73:397.

Reddy KS, Sahni P, Pande GK, Nundy S. Research in Indian medical institutes. Natl Med J India 1991;4:90-92.

Rosenberg SA. Secrecy in medical research. N Engl J Med 1996;334:392-394.

Varmus H, Satcher D. Ethical complexities of conducting research in developing countries. NEJM 1997;337:1003-1005.

Madhukar Pai, MD, DNB
Consultant, Community Medicine & Epidemiology
Sundaram Medical Foundation, Anna Nagar, Madras – 600 040

BACKGROUND PAPER: 5
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Ethics in medical research in India

An overview

Sandhya Srinivasan

Introduction

A number of controversies on the ethics of research in developing countries, and reports of India's growing importance as a site for international research, have highlighted the urgent need for discussion of the subject. For example, trials of drugs to prevent vertical transmission of HIV, involving over 16,000 pregnant HIV-positive women in Asia and Africa, were criticised for using placebo controls despite the availability of an effective treatment[2]. More recently, a study of risk factors for HIV transmission in Uganda intentionally did not provide STD treatment to the control group, or ensure partner notification of HIV-positive participants, in order to obtain its results[3]. Such studies could not have been conducted in developed countries.

This subject is of particular relevance to India as it promises to become a major site for research on human beings. There is, already, a long and controversial history of contraceptive testing in this country[4], and more recently, research has commenced on HIV vaccines and AIDS drugs[5].

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[2] Lurie P et al: Ethical, behavioral, and social aspects of HIV vaccine trials in developing countries. *Journal of the American Medical Association* 1994 January 26; 271: 295-301
Lurie P, Wolfe S: Unethical trials of interventions to reduce perinatal transmission of the Human Immunodeficiency Virus in developing countries. *New England Journal of Medicine* 1997; 337: 853-6.

[3] Angell M: Investigators' responsibilities for human subjects in developing countries *The New England Journal of Medicine* 2000; 342 (13)
Quinn TC et al: Viral load and heterosexual transmission of Human Immunodeficiency Virus Type 1 *The New England Journal of Medicine* 2000; 342 (13)
Wawer MJ et al: Control of sexually transmitted diseases for AIDS prevention in Uganda: a randomised community trial. *Lancet* 1999 February 13; 353 (9152): 525-35.

[4] Bauxamana R: The price of assistance: the family planning programme in India *Socialist Health Review* 1985 March; 1(4): 148-159.
Kusha: Contraceptive research in India. *Socialist Health Review* 1985 March; 1(4): 166-70, 178
Prakash P: Injectable contraceptives. *MFC Bulletin* 1985 May; 113: 1-3.
Sathyamala C: Depot-medroxyprogesterone Acetate and breast cancer: a critique of the WHO's multinational case-control study. *MFC Bulletin* 1995 July; 220: 1-5.

In addition, India's large population with diseases of the poor as well as of the better-off has attracted a number of contract research companies undertaking clinical trials for pharmaceutical companies in the West, to make it a "world centre" for drug testing. The potential returns are believed to be "tremendous". A clinical trial here would reportedly cost a third of what it would in the US, and the US Food and Drugs Administration may soon accept data from trials anywhere in the world, as long as they meet its standards of data collection. It is worth noting that poor standards of health care have been cited as one of the reasons trials in India will be cheaper and give results faster than in the US[6]. Fears have been expressed that the region will become a laboratory for testing drugs for developed countries[7].

Meanwhile, proposed changes in international ethical guidelines for research on humans have prompted some concern. The World Medical Association is considering amendments to the Declaration of Helsinki. Similar modifications are reportedly being

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Report of the women and health cell meeting, Wardha, January 4-5, 1995. *MFC Bulletin*. 1995 January-February; 214-215: 1-6.
Discussion on Depo-Provera. *MFC Bulletin*.1995 January-February; 214-215: 12-16.
Forum for Women's Health: The case against anti-fertility vaccines. *MFC Bulletin*. 1995 May; 218: 1-8.
Phadke A: An alternative view about Depo-Provera. *MFC Bulletin* 1995 August-September; 221-222: 10-13, 16.
Mehra P: Of human guinea pigs. *Illustrated Weekly of India*. May 2, 1992.
Ravindra RP: Reject the injectables. *Issues in Medical Ethics* 1999; 7 (2): 47.
Saheli: *Target practice: anti-fertility vaccines and women's health*. Delhi, 1998.
Women and health cell of the Medico Friend Circle: Submission to the National Human Rights Commission on AFV immuno-contraceptives. *MFC Bulletin*, March-April 1996: 10

[5] Raghunathan S: India launches AIDS vaccine programme. IAVI Report 1999; 4 (2): 15. Quoted by Mehendale S: Ethical considerations in AIDS vaccine trials. *Issues in Medical Ethics* 2000; 8(1): 13-15.
India agrees for AIDS vaccine trial, *Indian Express*, Mumbai, November 10, 1998;
India okays AIDS vaccine trial, *The Times of India*, November 10, 1998.
Chinai R: Preventing HIV transmission. *The Times of India*, Mumbai, November 9,10, 1998.

[6] Bagla P: India Creates Novel Brain Research Center. *Science* 1999 October 1; 286: 25b-27b.
Anonymous: Clinical trials in India: patient capital. 2000 January 29.
Chowdhury J: Lab tests new drugs on human volunteers. *The Times of India*, Bombay, October 10, 1995.
Ahmed M: Smithkline Beecham mulls clinical data management centre. *Business Standard*, Calcutta, February 24, 1998.
James JS: India (AIDS) research opportunities, price and patent problems. Interview with David Scondras. *AIDS Treatment News*, June 18, 1999; Issue 321.

[7] Bidwai P: The Indo-US Vaccine Action Programme: a recipe for disaster. *MFC Bulletin* 1989 February; 148: 1-5.
Chowdhury Z: Research: a method of colonization. *MFC Bulletin* 1981 February; 62: 1-2, 6.

discussed by the Council for International Organisations of Medical Sciences in the International Ethical Norms for Biomedical Research Involving Human Subjects[8]. One of these is that the level of health care required for participants will be determined not by the standards of the sponsoring researchers' country, but by the "local standard of care". Initial opposition has postponed further discussion on the subject, but it has not been dismissed altogether[9].

In India, guidelines for biomedical research involving humans[10], developed by the Indian Council of Medical Research (ICMR), have been circulated for discussion for some time, but are yet to be finalised.

Research ethics in India should be discussed in the context of all these developments.

Medical ethics in India

The ICMR's 1997 guidelines will join a relatively sparse body of literature on medical ethics, in practice and in research, in India today. Current medical practice does not seem to have produced a well-developed discussion on the subject. Traditional systems of medicine were clearly associated with one or the other religious world-view[11] and social system, perhaps more easily enabling the development of coherent sets of guidelines for medical practice. Discussion of medical ethics may be more complex in an environment of multiple systems of medicine (dominated by allopathy), and the unregulated growth of privately-financed health services and medical colleges focusing on commercial gain. Despite frequent reports of negligent medical practice, institutional avenues for the redressal of such complaints have been relatively ineffective, as are efforts to activate medical councils. Consumer rights organisations and other voluntary organisations to promote ethical practice have been a response to this situation. Still, much of this recent discussion on medical ethics has been a statement of the standards of good practice rather than an analysis of the ethical conflicts in medical practice, and the link between the principles involved and the conditions in which they are discussed.

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[8] Schuklenk U: International research ethics guidelines to be revised in nearly complete secrecy. *Monash Bioethics Review* 1999; 18(3)

[9] Email update from Peter Lurie.

[10] ICMR: Draft consultative document on 'Ethical guidelines on biomedical research involving human subjects.' 1997.

[11] Francis CM: Medical ethics in India: ancient and modern (I). *Issues in Medical Ethics* 1996 October-December; 4 (4): 115-8
Francis CM: Medical ethics in India: ancient and modern (II). *Issues in Medical Ethics* 1997 January-March; 5(1): 3-6
Christakis NA: Ethics are local: engaging cross-cultural variation in the ethics for clinical research. *Social Science Medicine* 1992; 35 (9): 1079-1091.
D'souza M: The ethical principles followed by *vaidus*. *Issues in Medical Ethics* 1999 January-March; 7 (1): 15.

Ethics of biomedical research in India

Researchers embarking on a study involving human beings must ask themselves a number of questions before starting work. Is the research necessary and relevant to the community being studied? How does one ensure that researchers' intentions are not unduly influenced by funding agencies which may have their own agendas? Is the researcher competent and does s/he have the resources necessary to carry out the work properly? Are there any risks to potential participants, and if so, should the research considered at all? Have participants given their informed and voluntary consent? What measures are taken to protect participants' privacy, and to prevent their exploitation? What measures are taken to ensure that the community benefits from the research findings? Such issues must be considered and reckoned with before the study starts, during the research process, and once work is completed[12].

Do researchers in India routinely ask such questions of themselves? In the absence of a central registry of biomedical research in the country, it may be impossible to arrive at a reliable picture of the quality of research in this country: how much money is spent, by whom, what researchers set out to study, study designs, who the participants are, whether the study have received clearance from an ethics committee, the research findings. their application, and so on. However, some published accounts suggest that reflection on the ethical issues involved in medical research on human beings is not a serious concern of researchers in India.

One measure of ethics in research is its relevance. Reviews of articles from India in indexed publications between 1981 and 1985 found a poor correlation between the subject matter of research in India and research needs as identified by morbidity and mortality data. The majority of research focused on problems more commonly found in wealthy societies, such as heart disease, cancer and neurological disorders, which concern a relatively small proportion of the Indian population. Little research concerned problems common in India, such as malaria, tuberculosis, or blindness[13]. Research in public hospitals has been questioned for its concentration on technology-intensive research in super-specialities rather than in fields relevant to Indian conditions such as infectious diseases, occupational health, trauma and burns management[14].

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[12] Pilgaokar A: Ethics in biomedical research. Unpublished paper presented at the annual meeting of the Medico Friend Circle, 1995.
ICMR, 1997, op cit.

[13] Arunachalam S: How relevant is medical research done in India? A study based on Medline. *Current Science* 1997 June; 72 (12): 912-22.
Arunachalam S: Does India perform medical research in areas where it is most needed? *National Medical Journal of India* 1998; 11 (1): 27-34.
Nundy S: What can be done about Indian medical research? *National Medical Journal of India* 1998 January-February; 11(1):1-2

This follows trends in international research. A recent report concludes that less than less than 10 per cent of the world's health research budget is spent on conditions that account for 90 per cent of global disease. Though pneumonia and diarrhoeal disease are believed to represent about 11 per cent of the total global burden of disease, only about 0.2 per cent of health research funding is spent in this area[15].

The gap between research and the community's needs is reflected in the practice of medicine, which is driven by the demands of commerce and prestige rather than by a research-based understanding of disease, its causes and treatment[16].

Questionnaire-based studies of medical personnel[17] provide some insight into the perceptions and background of people doing research. The vast majority of respondents do not report any training in medical ethics. More than a fourth of respondents in one study[18] reported that there were no ethical problems to be encountered in medical research. A tiny fraction of them were aware of all components of informed consent. Varying proportions of respondents recognised the existence of ethical issues in different medical situations. In one study, only 44 per cent believed that there were any ethical issues to consider in community research[19]. Almost half of those who undertook research obtained only oral consent from participants. Physicians who had done an orientation course in medical ethics, and those with prior research experience, were more aware of ethical issues[20].

The conduct of ethical research requires the presence of an active ethics committee. However, it has been suggested that ethics committees function poorly in the absence of institutional support. They are often set up in order to enable clearance of research proposals; committee members do not have the training, time or interest to fulfil their

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[14] Nagral A: Research in public hospitals of Bombay. Paper presented at a meeting of the Medico Friend Circle, Mumbai June 26, 1994.

[15] Research does not reflect global disease burden *BMJ* 2000; 320:1228

[16] Sethi PK: Orthopaedics in an unjust world. *Issues in Medical Ethics* 1999 July-September 86-91.

[17] Murthy RS et al: Ethical issues in medicine: an opinion survey. Paper presented at the International Conference on health policy: ethics and human values, New Delhi, 1986. C-46-49. Sriram TG, et al: Opinion survey of physicians on ethical issues in medical research. *Journal of the Indian Medical Association* 1991 July; 89(7): 187-90.

[18] Murthy RS et al, op cit.

[19] Murthy RS et al, op cit.

[20] Sriram TG, et al, op cit

responsibilities; and institutional politics corrupt the review process. Finally, proceedings of committee meetings are kept confidential, preventing transparency in functioning [21].

Some institutions are known to have relatively active ethics committees, which have worked to consciously develop an ethical review process. However, these are perceived to be the exception rather than the rule.

In fact, an ICMR survey of its affiliated institutions revealed that many of these institutions did not have active ethics committees, and the ICMR itself does not have the infrastructure necessary to monitor their functioning[22].

Ethical research also requires the dissemination of research findings, particularly to the community of participants for their benefit. However, such transparency may rarely exist. For example, official research programmes do not necessarily describe the strategy by which research findings is transmitted to the medical community and the affected public [23]. Research sponsored by pharmaceutical companies is often controlled by them, and negative findings are not submitted for publication[24].

Few institutions have guidelines establishing authorship of research publications[25]. Similarly, publications and research organisations do not always have clear-cut guidelines for submission, including a statement of the ethical review process[26]. Medical journals report receiving many submissions describing ethically reprehensible research[27].

In sum, ethics does not seem to be a priority in medical research in India today. This situation is a product of many factors. Research seems to be driven by the economic opportunities it presents, and the needs articulated by the group funding the research. Trends in medical practice focus on profits and favour technology-intensive treatments, and this produces research questions irrelevant to the problems of the majority. Ethics is not part of the curriculum in all but a few medical colleges. Inequalities already inherent in the doctor-patient relationship are heightened by widespread poverty, lack of access to

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[21] Pandya SK: Hospital ethics committee. *Issues in Medical Ethics* 1996 April-June; 4(2): 51-3.

[22] V Muthuswamy, personal communication.

[23] MFC team, Bangalore: Medical research in Bhopal. *Medico Friend Circle Bulletin* 1985 April; 112: 1-4.

[24] Nagral A, op cit.

[25] Ganatra RD: Ethics of authorship of scientific papers. *Issues in Medical Ethics* 1996 July-September; 4(3): 78-80.
Jesani A: Ethics of authorship. *Issues in Medical Ethics* 1996 October-December; 4(4): 127.

[26] Amar Jesani, SK Pandya, Anil Pilgaokar, Yash Lokhandwala, personal communications.

[27] P Sahni, personal communication.

health care, and the belief that health care is not a right but a privilege. Existing guidelines and monitoring infrastructures are inadequate.

Some ethical issues in health research

Without a comprehensive survey of research, it is difficult to assert what the most commonly encountered ethical issues in India are. However, it is suggested that the fundamental ethical questions faced by researchers in India today relate to the forces involved in formulating research questions, and to the vulnerability of poor populations.

Informed consent: The difficulties of getting informed consent are exacerbated by the low priority accorded to it by researchers, and by the conditions in which potential participants live. It may be difficult to obtain informed consent from the poor -- not because of literacy levels but because their need for health care may make them more vulnerable. Truly informed consent is crucial to ethical research.

Medical personnel often report that patient/ participant illiteracy is the commonest constraint to obtaining informed consent. In fact, a study showed that patients are able to understand details of their treatment, though they had more difficulties if they were older, poorer or less educated [28]. Participants in medical research must also be informed that they may not benefit, though the information gained through their participation would benefit others. Potential participants may see the trial as an opportunity for some health care.

Though researchers conducting a leprosy vaccine trial reported conscious efforts to obtain written informed consent from the individual participants, only 38 per cent of those surveyed were aware that the vaccine was meant to protect against leprosy. As many as 21 per cent said they did not know the purpose of the vaccine. It is also worth noting that the research team felt it best not to mention, in the consent form, the double-blind nature of the study, the multiple arms of the trial, or the presence of a placebo arm, though the study design was discussed with the ethics committee supervising the trial[29].

Study design: Ethical issues related to study design will probably become a significant subject of debate in the future. With the launch of a number of HIV-related trials in India, controversies already hotly debated elsewhere are becoming articulated here. At least one study was reportedly forced to change its design following protests from local organisations[30]. Ethical issues relating to the proposed HIV vaccine trials in India have

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[28] Sanwal AK et al:. Informed consent in Indian patients. *Journal of the Royal Society of Medicine* 1996 Apr; 89(4):196-8 (abstract)

[29] Gupte MD and Sampath DK: Ethical issues considered in Tamil Nadu leprosy vaccine trial. *Issues in Medical Ethics* 2000; 8 (1): 10-12.

[30] Meena Seshu, Sangli, personal communication.

been discussed in detail recently[31]. It is pointed out that trials among groups with a high incidence of HIV infection are easier and more cost-effective, especially if done on people who have not had access to anti-retroviral therapy. Opposition has already been expressed to the proposal that participants with break-through infection need not receive three-drug therapy because it is not financially sustainable[32].

Confidentiality: Researchers sometimes do not respect participants' right to complete confidentiality. For example, presentations at medical conferences have on occasion displayed unmasked photographs of participants, a blatant violation of their privacy. On the other hand, some research projects report special efforts to preserve participant confidentiality[33].

Follow-up: Follow-up of participants is both an ethical requirement and a scientific necessity for good research. Yet there are many indications that researchers do not bother to maintain long-term contact with participants, even as they report the findings of such research. This has been often reported in contraceptive trials.

Use of research: Finally, the proposed and actual use of data presents a major ethical issue. How many poor Indians can afford any of the drugs being tested on them? Is it ethical to test drugs or procedures which will not be available to the community after the research is over? Pharmaceutical companies have on occasion admitted that they cannot provide drugs found effective through trials in poor countries, to the participating community.

International guidelines in medical research

International statements on modern medical research ethics date back to the Nuremberg Code of 1947, a response to atrocities committed by Nazi doctors on prisoners in the name of medical research. The Nuremberg Code was supplemented by the World Medical Association's Declaration of Helsinki[34], first presented in 1964, and revised a number of times since then. Both documents lay down general principles for ethical medical research on human beings. The Declaration states that research must be properly

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[31] Mehendale Sanjay: Ethical considerations in AIDS vaccine trials. *Issues in Medical Ethics.* 2000; 8 (1): 13-15.

[32] U Schulenk U: Ethics and AIDS vaccine trials: a response. Letter *Issues in Medical Ethics* 2000; 8 (2): 37

[33] Ganatra B et al: Induced abortions in rural Maharashtra: prevalence and patterns. Paper presented at workshop on reproductive health in India, new evidence and issues, February 28-March 1, 2000.

[34] World Medical Association Declaration of Helsinki. Recommendations guiding physicians in biomedical research involving human subjects. Adopted by the 18th World Medical Assembly, June 1964, amended in October 1975, October 1983, September 1989 and October 1996.

designed and carried out by competent people, risks assessed, participants' integrity preserved, informed consent obtained, results accurately published. The Helsinki Declaration's guidelines on clinical research emphasise that physicians' responsibilities to their patients override their role as researchers. Even when doing non-clinical biomedical research, "the interest of science and society should never take precedence over considerations related to the well-being of the subject."

Other important documents on the subject include the International Guidelines for Ethical Review of Epidemiological Studies and the International Ethical Guidelines for Biomedical Research Involving Human Subjects. Such documents lay the foundation for protection of research participants. Controversies regarding certain advances in research have led to the development of national guidelines on, for example, genetic research, or cloning.

International guidelines have served to set standards for research. They have also been the foundation of national guidelines in various countries. Such guidelines can guide the practice of research, in the presence of other enabling factors. Some of these enabling factors may be: the infrastructure for monitoring research ethics, the possibility, in a given country, of legal action against unethical research, a doctor-patient relationship which is less conducive to abuse by doctors, and functioning health services.

International guidelines also serve as a basis for discussion in the international community, as is reflected by current criticism of the proposed changes in these guidelines.

Further, organisations such as the National Institutes of Health and the Centers for Disease Control in the US require that research funded by them in other countries meet their ethical guidelines.

However, most of the frequently cited examples of unethical research in India are cross-cultural, whether funded by national health organisations, by pharmaceutical companies in the West, or by international organisations[35]. It is also worth noting that a report on quinacrine sterilisation of thousands of poor women in Asia without their informed consent -- accepted to be blatantly unethical research -- was published in at least one reputed journal in the West[36].

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[35] The US Centers for Disease Control and National Institutes of Health funded nine of 15 controversial trials on vertical transmission of HIV. Private organisations in the West funded quinacrine sterilisation in Asia and testing of Bovine Immunodeficiency Virus vaccine on HIV patients in Mumbai.

[36] Hieu DT et al: 31,781 cases of non-surgical female sterilisation with quinacrine pellets in Vietnam. *Lancet* 1993; 342:213-17.

National guidelines on biomedical research ethics

There is no government body responsible for maintaining ethical standards in all research conducted in this country. However, the Indian Council for Medical Research is responsible for the ethical standards of research in its institutions.

It was only in 1980 that the ICMR issued its first policy statement on the subject[37]. The document provided a brief description of basic ethical principles, the need for informed consent, particularly when concerning research on vulnerable groups, the question of inducements, the role of an ethics committee, publication policies and so on. It also referred to requirements for the clinical evaluation of new drugs, and of traditional medicinal plants.

All research institutions were urged to set up ethics committees to review research proposals and monitor on-going research. Proposals would have to be approved by the research institution's ethics committee in order for the ICMR to consider their funding. The ICMR would expect the local ethics committee to monitor research, but reserved the right to review it as well. If the research institution did not have such a committee at the time, the ICMR would provide the necessary review on a short-term basis. Research papers would not be considered for publication in the ICMR's journal, the *Indian Journal of Medical Research*, without evidence of approval from an ethical committee.

The 1980 policy statement is supplemented by documents referring to research in specific areas. Some of these are listed below:

In 1988, the Drug Controller of India (DCI) issued a gazette notification, 'Requirement and guidelines on clinical trials for import and manufacture of new drugs, for the first time bringing in rules on drug testing in India.

In 1994, the ICMR published guidelines for the conduct of clinical trials for contraceptives[38]. This document describes the various steps mandatory to the contraceptive approval process and identifies the institution responsible for conducting the research at different stages, as well as the responsibility of investigators and monitoring authorities. The ICMR's ethical committee would review all pre-clinical documentation, data, and proposed trial protocol, while separate approval from the DCI regarding the trial protocol would be mandatory for each phase of the trial. However, though two members of the ICMR's ethics committee have signed the document, there is no mention of the manner in which participants would be recruited, the importance of informed consent, the need to provide treatment of side-effects or complications, or long-

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[37] ICMR: Policy statement on ethical considerations involved in research on human subjects. 1980.

[38] ICMR guidelines on responsibililty for clinical trials of contraceptives conducted in India. ICMR, New Delhi, 1994.

term follow-up of trial participants. Nor do the guidelines say anything about the history of ethical controversies in contraceptive research.

In 1997, the government published revised guidelines to monitor and regulate the exchange of human biological material as part of collaborative biomedical research. It exempted "recognised labs such as WHO collaborative centres or WHO reference centres", but required that all other research projects involving the export of biological tissues get permission from an ICMR committee[39].

These documents do not identify or comment on the relevant ethical issues in depth, and do not provide a comprehensive framework for research ethics. In any case, they have had limited influence on research, partly because the ICMR has been unable to provide institutional support towards implementation.

Nor has it been possible to rely on medical councils to ensure that doctors follow the Code of Medical Ethics. Besides, questionable research sometimes does not depend exclusively on Indian doctors. For example, the quinacrine sterilisation method was also taught to a network of unlicensed practitioners, and the entire project was coordinated by two American doctors [40].

In sum, though some institutions are able to develop and implement internal guidelines, and seem motivated on their own to produce ethical research, current ethical guidelines and regulations have had limited influence on the conduct of medical research.

For example, though the ICMR refused to fund an Indo-US research project involving implantation of foetal tissue in the eyes of Indian patients with retinitis pigmentosa, pointing out that "...undertaking clinical trials on Indian subjects for an experiment which was not being conducted on US subjects was not ethical," it stated that it could not stop the research[41].

Similarly, US-based doctors contacted people with HIV infection through a Bombay-based organisation, and injected them with a vaccine based on a strain of bovine immunodeficiency virus. Action was taken against the local organisation involved only because one of the patients' relatives filed a criminal complaint[42].

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[39] Mudur G: India concerned at export of genetic material. *BMJ* 1996; 312: 464.
Government of India Ministry of Health and Family Welfare. Guidelines for exchange of human biological material for biomedical research purposes, November 19, 1997.

[40] R Dasgupta, personal communication.

[41] Mudur G: India to control foreign research involving Indian patients *BMJ* 1997; 314: 165
Special correspondent: Foetal tissue transplant: ICMR clarifies. *The Hindu* (Madras), January 2, 1997.

[42] Mudur G: Doctor in India arrested over irregularities in trial of vaccine *BMJ* 1999; 318: 1308.

More than 30,000 poor Indian women were sterilised with the anti-malarial drug quinacrine, with no evidence of informed consent, monitoring or follow-up, before the DCI gave an undertaking to the Supreme Court to ban the procedure which is unapproved by the WHO. Quinacrine sterilisation was promoted openly at professional meetings of gynaecologists, and through networks of practitioners. The drug controller was forced to act only after a writ petition was filed in the Supreme Court challenging the practice as unethical. Incidentally, the court has not asked for a follow-up of the women who have been experimented on[43].

ICMR draft guidelines on biomedical research, 1997

The ICMR is currently examining a Draft Consultative Document on Ethical Guidelines on Biomedical Research Involving Human Subjects, 1997[44]*. The guidelines have been circulated for public discussion and a revised document based on these discussions is expected to be finalised shortly. Further discussion is to take place towards their implementation, and the development of relevant legislation*[45].

The general principles set out in the document are admirable: The research must be essential; informed, voluntary consent must be obtained; participants should not be exploited; their privacy must be respected; risks must be minimised; researchers should be competent; procedural requirements must be complied with; the findings should be applied for the benefit of all; all those connected with the research should be held responsible for its ethical functioning; and the guidelines should be complied with both in letter and in spirit.

However, the guidelines have been criticised for not responding to gender and class inequalities inherent in Indian society: "Ethical guidelines should go beyond technicalities and build effective safeguards so that the unequal power relationship between researchers and subjects is neutralised and no new avenues of exploitation of research subjects are opened up... The current document falls short of these objectives."[46]

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[43] Pollack AE and Carignan CS: The use of quinacrine pellets for non-surgical female sterilisation. *Reproductive Health Matters* 1993 November; 2: 119-122.
Quinacrine sterilisation still being done despite expert advice against it. *Reproductive Health Matters* 1997 May; 9: 176.
Rao M: Quinacrine Sterilisation Trials: A scientific scandal? *Economic and Political Weekly 1998* March 28.
Supreme Court of India bans import, manufacturing, sale and distribution of quinacrine in pellet form for use as a contraceptive. *The Hindu*, August 17, 1998.

[44] ICMR, 1997, op cit.

[45] V Muthuswamy, R Narayan, personal communications.

The proposed guidelines identify five areas for discussion: human genetics research; transplantation research including foetal tissue transplantation; clinical evaluation of drugs/ devices/ vaccines/ herbal remedies; epidemiological research and assisted reproductive technologies.

The guidelines give equal importance to areas commonly researched and those of limited relevance in India. A large part of the document is devoted to the ethics of research in genetic testing, organ transplantation and assisted reproductive technology, though there is little original research in these areas in India. What is needed in these areas is a clear definition of what research constitutes in these areas, and a statement on the relationship between clinical practice and research.

On the other hand, frequently researched areas are not discussed in detail. For example, the proposed guidelines have little to say about the ethical issues involved in research on drugs and vaccines[47]. They also do not make a strong statement on the ethical issues related to collaborative research, an area which is receiving much attention for its potential to exploit poor communities[48].

They do not even mention contraceptive testing, though this may deserve a separate discussion in the guidelines. A detailed set of suggestions has been made for this area[49].

The guidelines presume that education is linked to informed consent, and the use of community leaders to obtain consent is supported. "With large segments of our population, given their level of education, the full understanding in the sense of industrialised countries may not be achievable."[50] This presumption has been challenged by many researchers[51]. It has been suggested that the draft undermines basic principles by indicating that the importance of research could override the need for written informed consent by the individual participant for each study [52].

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[46] Saheli Women's Resource Centre: ICMR draft ethical guidelines: a critique. *Issues in Medical Ethics* 2000; 8 (1): 20-21.

[47] This section is based on comments from interviews with a number of medical professionals and activists, including SK Pandya, A Pilgaokar and Y Lokhandwala.

[48] Schuklenk U, 1999, op cit.

[49] Saheli Women's Health Collective, op. cit.

[50] ICMR, 1997, op cit., pp. 62-3.

[51] R Narayan, personal communication.

[52] Saheli Women's Health Collective, op. cit

The guidelines on epidemiological research do not discuss the importance of the subject of research. It can be argued that truly ethical research must look for solutions to the health problems specific to this country's people. It has already been suggested that much research in India does not address the needs of the community[53].

There is nothing said about the ethical implications of various trial designs, ignoring the current debate on the use of placebo controls when a proven treatment exists. They only note that information on the drug research protocol should include "a description of plans to withdraw or withhold standard therapies in the course of research"

The 1997 guidelines do not directly address laboratory-based research which may use established drugs or procedures, including invasive and possibly risky procedures[54]. They do not address medical therapy, surgical operations, radiotherapy, chemotherapy and other interventions being carried out in day-to-day practice. Nor do they address the need to follow up trial drop-outs, the need for drugs found effective in trials to remain available to the participants, and the need for a regularly updated database on the medical research being conducted in the country.[55]

Proposed code for social science and health research

The proposed draft code of conduct on ethics in social sciences and health research[56] is a more broad-based document than are the ICMR guidelines and is directed at all research activity in the country. It is hoped that the finalised code is adopted after discussion by institutions and individual researchers, to guide research practice.

The code notes that with the growth in research and in funding for research, inadequate self-regulation enhances the potential for unethical research. It articulates the broad principles governing social science and health research, covering issues in research ethics ranging from the pressures of funding agencies and the need to protect participants, to publication ethics and the implementation process. It also goes beyond the ICMR guidelines in some areas, articulating in detail issues concerning the relationship between researchers, informed consent, participants' rights, data use and reporting of findings.

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[53] Arunachalam S, 1998, op cit.

[54] Mario Vaz, personal communication.

[55] Pandya SK: Organising a public debate: ethical guidelines on biomedical research in humans. *National Medical Journal of India* 1998; 11(6): 294-5.

[56] Shah G et al: Ethics in social sciences and health research: draft code of conduct. Centre for Enquiry into Health and Allied Themes, Mumbai, March 2000. Published in: *Economic and Political Weekly*, March 18-25, 2000.

The code may be more useful to researchers if accompanied by a practical framework to work through common ethical issues in the planning and undertaking of research. This would be particularly useful to researchers considering the low level of discussion on ethics in research. It could be presented as a set of questions requiring researchers to reflect on the research process and spell out possible ethical dilemmas and their resolution.

Given its broad scope to cover all social science and health research, the code does not focus on issues specific to medical research. For medical researchers, this framework could include issues specific to medical research. Some suggested questions for inclusion in this framework are:

- Do the expected benefits justify the research, and what assurance is there that the benefits reach the participants' community?
- In research on medical treatments otherwise unavailable to the participants, is there scope for inducement or coercion in the process of obtaining consent? What measures are taken to prevent such influences?
- If a laboratory-based research project involves risk to the participant and no medical benefit, how is it justified?
- In research which accompanies clinical practice, is there a conflict between the clinician's and the researcher's roles, and if so, how is this conflict resolved?
- Is there long-term follow-up for research on health interventions?
- Does the study design raise any ethical issues? How are they resolved?

The proposed code is being discussed for voluntary implementation by institutions and individuals doing research. This would be an important step towards encouraging ethical research. It is possible that the publicity given to such a code will put pressure on institutions and individuals to adopt the code and discourage researchers from violating the guidelines.

In the long run, however, for any code to be effective, it must apply to all research in this country. The commercial gains obtained by medical research encourage organisations and individuals to ignore ethical codes unless it is in their interest to follow them. Many people concerned with ethics in biomedical research have expressed the need for a monitoring and enforcement machinery of some sort, which would cover all such research on humans done in India.

For the code to be most effective, links also need to be established with existing national and international organisations responsible for ethical research, and with medical journals in which the research is published. At the same time, implementation would have to be supported by a multi-pronged effort to promote ethical principles in research, through medical education and through discussion in the larger community[57].

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[57] R Narayan, CM Francis, personal communication.

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Published material was collected from a number of sources, including clippings files in the Centre for Education and Documentation, Mumbai; available publications on medical ethics at the libraries of the Centre for Enquiry into Health and Allied Themes, Mumbai, the Community Health Cell, Bangalore, and the Indian Council of Medical Research, Delhi; and internet searches.

Ms. Sandhya Srinivasan
Executive Editor,
Issues in Medical Ethics
8 Seadoll, 54 Chimbai Road, Bandra West, Mumbai 400050

BACKGROUND PAPER: 6
Draft Not To Be Quoted

Ethical Issues in Social Science Research
Some Basic Concepts

Tejal Barai

What do we mean when we say "Ethics" in Social Science Research?

Social Science is a reflexive science. It essentially means that it is a study of human beings by human beings, including those beyond the researcher and the participant, resulting in certain outcomes. The significance of these outcomes may be different for different people, including both the researcher and the participant, even the sponsors or funders. It is as result of this very intrinsic nature of Social Science that ethical dilemmas arise (Barnes, 1977). Ethical dilemmas arise at all stages of research. What someone, may see as an "ethical" dilemma, can be seen as an obstacle to research by another. Moreover these dilemmas or obstacle may as a result of external factors or can arise as a result of certain aspects or facets of the study. However, what is common between both these perspectives is that such a situation, when it arises, and it inevitably does, has the potential to cause damage, injury or harm. The harms not just to the participants of research but also to the research discipline thus affecting its credibility. The injury might not have been anticipated, or it might have been anticipated but not addressed. *The sensitivity and the awareness to the possibility of this injury or harm, and the conscious and honest effort to prevent and resolve these issues is what we refer to here as ethics in research.*

From the selection of the research problem to the publication of the research findings, research is ripe with situations and circumstances that raise ethical issues. A researcher being pressured to alter the findings of his study, completing questionnaires without venturing into the field, a study conducted on a handful of critically ill patients to test their level of anxiety. Or consider the case where women might be interviewed on issues of marital relationships or sexual behaviour in the presence of other members of the community. All these instances raise serious ethical issues.

Every research carries some amount of risk, injury or harm either to the participants or to the society. Anticipating, addressing and minimizing these harms and risks is essential. Embarrassing questions such as those on sexual behaviour or issues related to morality can have an immense psychological impact. Thus harms need not be physical harms. Studies can thus be harmful, in the sense that they have the potential to affect the dignity, or cause anxiety, shame, embarrassment, self-doubts, loss of trust in social relations, loss of autonomy and even a lowered self esteem. (Stuart Cook). Harms can also be in the form of material harms, such as loss of land, or imposition of taxes or levy. It would then be a forgone conclusion that research that has the potential of causing excessive harm should not be undertaken[1].

This paper thus is a modest attempt to bring out some basic ethical issues associated with various areas and stages of research.

Relevance of Research

Let us then begin with the essentiality or the relevance of research. When we decide to do research on a particular aspect of an issue, what are the reasons behind it? The most important motivating factor would be a personal interest in the issue. There are other factors too that affect our choice of research and these are directly related to the issue itself. Among these include, dearth of knowledge on that issue, and a need to understand and or increase awareness towards it. A research problem could be of macro - relevance such as its contribution to the overall development of our country, or it could be of micro-relevance, that is, it could be an effort towards understanding the situation or say the specific needs of a community. But the bottomline is that it should be relevant and the need justified.

Thus the function of social science research is to develop knowledge about humans and exploring the scope of this knowledge for practical use. These we see as some of the benefits of research. Thus it recognizes pure research as well as applied research, in the form of solving concrete problems of society. Neither of these values should be spurned. "Knowledge without application of knowledge often leads to still birth". Social research in India will also have to cope with the problems of India's development, and social science researchers should not absolve themselves from the responsibility of the social implications of their research. (Baidya Nath Varma, 1965). The Indian Centre for Social Council Science Research in its various reports and seminars have time and again acknowledged that research studies should have some amount of social relevance. For instance in their Survey of Research in Sociology and Social Anthropology 1969-1979, they have criticized some of the research studies of the said decade for being repetitive, low quality irrelevant. They have further identified ailments that Indian research suffered from. These include "lack of innovative thinking, voluminous non-explanatory knowledge, sweeping generalizations and shoddiness in research." (Though not in all the research studies). Indian sociologists, anthropologists, economists, and researchers from all the branches of social sciences have been stressing the need for undertaking relevant research for a very long time (Bhatnagar, 1981). Studies where the findings reveal that high school students are more interested in reading stories than they are in reading newspapers have been

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[1] Yes, "excessive harm", can lead to a number of questions – what is excessive harm? How does one decide how much is excessive harm? However, it needs to stressed that where the potential for excessive harm exists, it can be very visibly judged. For instance the potential for harm looking into the mental state of HIV positive patients would be much more than a retrospective study looking into the mental state of accident victims.

criticized on the basis of how some social science researchers go about finding very obvious facts. (Chatterjee, 1967).

The issue of relevance or rather non-relevance stands strong even today. Consider then, an issue where a lot of research has already been done, that too on the same aspect, to such an extent that the same methodology and tools are used. For instance, if I were interested in doing a research study that aims to find out the state of mind or the anxiety of critically ill patients what are the questions that can be raised? It can raise the question of justification of such a research, where there is already a vast amount of reliable information and especially since the research deals with participants in a very critical state in both physical as well as psychological terms. The research would lead to subjecting these critically ill patients, who are already stressed and suffer from anxiety, to more stress and more anxiety. Further, if the study is done on a small sample, say of 30, of what value would the findings be of anyway? What if there is no of post-research counseling? Moreover is it not a known fact that critically ill patients would suffer from high levels of anxiety? Would it not have been better to do such a research as a retrospective study? How do the participants feel about being studied in that state, since is it not precisely this, i.e. the state of mind of these patients that was to be studied? Sutton and Schurman, during an investigation of a sensitive issue of organizational death, report that the informants thought that it was rude to study them at a time when they were in deep distress.

Concern is also been raised in the research community about research agendas being laid down by the knowledge industry of the West (Khanna R., 1996). Are such agendas and research priorities in tune with the priorities and realities of our country? The nature and directions of research are influenced by the funding or sponsoring agency. Researchers and issues that are considered safe may get the funding. (Michael Useem and Gary Marx, 1983). Directing the kind of research has its consequences on the on the social science discipline, since the researchers might simply go in for research that has a better chance of receiving funding, and these need not necessarily be the most pertinent or relevant. The issues of relevance then need to be seen against the backdrop of "neocolonialism" as some call it. It has been seen as a threat to the social science discipline in our country. Neo-colonialism seeks to "penetrate, to mystify and influence social science concerns in respect of theories and problems" (Singh, Y., 1991).

Research in social science is fast becoming an unregulated commercial sector, evident from among other things, the recent trend of bidding for projects. Researchers are also known to be doing a vast amount of research beyond their field of expertise, and studies are often done in a very hurried and superficial manner, with crude methodologies and crude techniques (K. P. Krishna, 1991). Irrelevant poorly justified and badly done research can have serious ethical implications and harms.

What kinds of researches are permissible in a society? Margaret Thatcher vetoed public funding of a survey on sexual behaviour. The US Secretary of Health and Human Services cancelled a large-scale survey on American teenagers as the questionnaire carried questions on sexual behaviour (despite the common view that people in the West are considerably open about such issues). These issues raise various questions about the extent to which research can encroach into a person's life and even about the validity of data in case of sensitive issues (Raymond, L., 1993).

Giving such an instance in our own country, Jawaharlal Nehru, for the 1951 Census, instructed the Census Commissioner not to collect data on castes (except scheduled castes and scheduled tribes as a result of the special attention guaranteed to them in the constitution). In Assam, the 1981 Census enumeration could not be done as a result of the controversy about data on mother tongue. It can however be argued that such data is essential, and the solution is not simply cutting out sensitive questions. Ignorance to these issues can prove even worse. Where such data are indispensable and relevant, effectively addressing the potential of harm and conflict that can be caused by such issues and scientific maturity to handle such data and its outcomes are essential. Effective addressing of these issues means that the potential to cause harm is minimised or preferably totally eliminated. For instance, anonymity of the identity of participants is one such way (Ashish Bose, 1991).[2]

Ethical Issues associated with the choice of Methodologies and choice of participants

Let us consider next, the choice of methodologies and of study population. How can these raise ethical issues? Apart from the fact that the sponsors and funders can direct these (Michael Useem and Gary Marx), the choice of inappropriate methodologies and study population itself can raise ethical issues. Whether it is the choice of research issue, the methodology or even selection of participants, questions need to be asked. How and what effect would a particular choice made by the researcher have on individual participants and on society? One may not be in a position to anticipate all the issues or harms involved, but the possibilities and the potential should be considered. Consider then an instance where Focus Group Discussions is the choice of methodology for getting information about abortion or sexual behaviour in rural areas. What are the possible harms that can be caused? First, considering the research setting, the choice of methodology is highly inappropriate in terms of responses. In a closed rural community, it would be rare that a woman openly admits having an abortion or a premarital affair. Where such facts are revealed by unfriendly neighbours, it leads to humiliation and ridiculing of the participants, and thus unethical. This view is echoed by Pertti Pelto who feels that sensitive issues such as sexual matters or other social unacceptable topics should not be introduced in group discussions. Thus choice of methodology and framing of research questions should be in consonant with the culture and background of the respondents. When not, the potential to cause harm increases.

Simply easy accessibility of participants is not a fair criterion of selection of participants in a study, since they might then have to bear the unfair share of burden. The Punjab Government, way back in the early twentieth century did not grant permission for a research trial to be conducted where the participants were prisoners (Das, et al.). However, on the other hand, there may be certain problems that are closely associated

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[2] See section on "Privacy, Anonymity and Confidentiality".

with a specific description of the population. Excluding them from research would result in poor understanding of their situation.

Moreover, assuming that the research is socially relevant, faulty methodologies or choice of participants could then lead to faulty policies, causing extensive harm. Researchers should bear in mind that information and decisions drawn from their research findings and report, have the potential of affecting not only individuals, but also an entire community or even a larger population. Methodologies and studies that give a very superficial view of a situation or a practice could spell disaster for that population. For instance, one single agricultural policy cannot be made applicable for an entire agricultural based population. A tribal population that practices shifting cultivation, and has a number of religious and cultural practices associated with it. A policy restricting it or altogether preventing it would not only prove disastrous but also end up in alienating the population. (Vidyarthi and Upadhya, 1981).

Integrity and Autonomy of Researchers and Institutions

What do we mean when we say Integrity and Autonomy of researchers? The challenges and dilemmas that any research poses are tremendous. Not all of these are associated directly to fieldwork. Moreover, what happens during fieldwork can be as a consequence of the researcher not having autonomy or the research being directed for him.

Integrity of a researcher implies that the researcher should not engage in unethical practices. It may be in the form of fabrication of data or manipulation to suit desired outcomes or in the form of false promises of confidentiality to secure co-operation. For instance a researcher assured confidentiality to prospective participants to learn about their religious practices. They were told that their secrets would not be revealed, when the entire purpose of such a study is to learn the customs, traditions as well as religious practices of this community. Moreover, there has been documentation of these, on the basis of information secured from other more co-operating participants (Jindel, 1975).

Challenges to integrity and autonomy can come from various sources, the funding agencies, the participants themselves or even at times the politicians. Researchers have also been known to be asked to change the research findings to suit a particular policy, which the agency or department under which the research is conducted, is interested in pushing forward or supporting. A government anthropologist was asked to change the findings of the study in a way so that the particular community could be declared a scheduled tribe (T. N. Madan, 1967). The anthropologist in question was a man of immense integrity but there might be others who succumb to such pressures. Researchers working in the government also face situations that raise dilemmas. For instance while evaluating developmental work, the researcher may be forced to be tactful in order to preserve "good relations" with colleagues. They could also be forced to change findings to fulfil the governments need to present a hopeful future to the citizens, and the fact that the government has monopoly over such data, can encourage such alteration of data. (Srinivas, 1972). The integrity of the researcher then plays a pivotal role, where researchers need to challenge such a recommendation, request or order.

Participants can themselves ask the researcher to fabricate data. For instance, during the Socio-economic survey of Hyderabad and Secunderabad City Area, by the Indian Institute of Economics, Hyderabad, one participants shared very honestly all facts about his ups and downs in the share market and as such. However, when the researcher needed to record his assets, he requested that smaller figures be entered than the actual. Instances such as these are common. Integrity also means that the researcher should continuously enhance his competence to do research, and herein lies the commitment to do research.

Instances such as these emphasise the need for competency, integrity and ethical sensitivity from all researchers, the researchers and research institutions and organizations. They should strive to protect their autonomy and freedom to research, and should not allow themselves to be put in a position that leads them to compromising their integrity. Researchers, institutions and organizations should protect their autonomy and should challenge questionable methodologies or other threats to ethics of research. In other words, a researcher should strive to protect his autonomy, *as far as it is in consonance with ethics* in research, and *contrary challenges exist.*

Autonomy of the Participants

The prospective participant after being furnished with the adequate information, has the right to choose whether he wants to be a part of the research, or otherwise. The exercise of this right freely is the principle of autonomy. The researcher should not impede on this right, by resorting to coercion, deception, or deprivation of essential information, or promise of unrealistic benefits or excessive reimbursement. Though the principle of autonomy presents an important yet difficult problem in our country, it is however indispensable. Apart from the fact that the concept of autonomous decision making being difficult, often curiosity, fear, a desire to be honourable to strangers or even a sense of flattery can be the motivating factors to participate (Hershfield, et al.). The respondents autonomy and dignity should be respected, and they should not only be told about the purpose of the research, but also their right to decline participation.

Where a distinct hierarchical structure exists, researchers can find it difficult to approach the participants in an independent way, since they are all working in an interdependent framework of rights and responsibilities. It is often acknowledged that here that participants are subtly coerced into "volunteering" (Sutton and Schurman). Such participation can even increase a person's emotional discomfort. The responsibilities of the researcher towards the participants thus increase.

Informed Consent

Where the principle of autonomy relies on information, we need to then address the issue of informed consent. What would be your first reaction when someone was to come to our door and request us to answer a few questions? Would you not want to know where is the person coming from, what is the purpose of the interview, or what kind of questions are going to be asked? In case you do agree to part with some time to answer the questions, would you not want to know if the information that you have given were confidential or would your name be identified in the reports? Why should participants of our studies not be given this same right to informed consent?

Informed consent taken orally is not acceptable. However, obtaining signatures from participants is not only difficult under our research settings, but often participants can also have fear of signing any written material. What is then suggested in the Draft Code of Conduct, is that information about the details of the project should be given in a manner and language they understand. This should be done in a verbal manner as well as in a *written* manner. The participants thus have a copy of all the information about the project with the names of the research team organisation, etc. The researchers should also provide the participants help in a form that is required and that can be given by the researchers. For instance in a study looking into the prevalence of gynaecological morbidity the researchers felt that to arrange for any required care was an important ethical aspect and essential also to seek participation (Koenig, M., et al, 1996).

The right to informed consent has various aspects to it and can give rise to some sticky areas (as can be the case about all aspects of research!). What if the participants were children? Consent then would need to be taken not just from the parents but also from the children (Ethics in Social Sciences and Health Research-A Draft Code of Conduct, EPW, 2000). Where the participants of research are children in an institutional setting say a remand home, then the consent to talk to the children and make them a part of their study needs to be taken from the "gatekeepers". Children, especially delinquent are known to be submissive and yielding in nature. (Kothari, S., et al., 1992). They may also carry with themselves a fear of "authority", in this case the remand home authorities, and may not be in a position to say no to something that was "sanctioned" by them. This thus makes it very essential for the researchers to not only make them aware of their right to decline participation without undesirable consequences.[3]

Research where the identity and purpose of the Researcher is not disclosed

There have been many debates in the West revolving around the permissibility of research where the identity and purpose of the researcher is not disclosed. The debate is never ending and any stand taken can lead to another debate. However there are a few very essential indispensable requirements which cannot be debated, and the issues needs to be seen beyond permissibility.

Let us first begin with acknowledging the fact that there are certain questions in research which cannot be revealed to the participants from fear of altered responses, thereby affecting the validity of the data. Where such is the case the need to skip or give a modified or altered briefing, needs to be justified, either to a broad independent peer review or an ethics board (EPW, 2000). The researcher not only needs to convince them about the essentiality of the research but also that the research cannot be conducted

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[3] The age of consent needs to be included in the draft after the Ethics meeting, to discuss the draft code (EPW 200).

otherwise. Moreover, it is very crucial that the researcher anticipates possible harms and benefits, minimize the anticipated harms and be prepared for the unanticipated ones. This is especially needed in study on sensitive issues. Further in such research the protection of the participants anonymity gains greater importance. A debriefing should essentially follow the study. Where the study has caused some kind of distress to the participants or where the participants are found in need of some help, the researcher should definitely provide so. Only where the research carries the above essential components should such a research be made permissible. However, a key question that needs to be asked here, has been very well put by Warwick, "should every social scientist who feels he has a laudable cause have the right to deceive respondents about the nature of surveys, engage in covert observation, and resort to other kinds of trickery?"

Some Perceptions of the Participants

It is found that in sensitive issues, the researchers need to have additional abilities, since the participants can expect something in return. The relationship between the researcher and the participants is especially different in studying sensitive topics, and raises even more complicated dilemmas. The researcher then has to be well equipped to provide support for two purposes. One to seek a more effective co-operation from the participants, and second, to enable the researchers themselves to handle the stress from researching sensitive issues.

Participants may find a particular research to be intrusive where the research deals with the private sphere of the participants (Lee, R., 1993). However *what is considered private and personal and what is not varies from person to person and community to community.* This makes it essential for researchers to view what is regarded as private and confidential to be viewed from a participant's perspective.

The presence of a researcher can also be seen with fear, from fear of sanction or from fear of disclosure of certain activities that the participants would not want to disclose. The researcher would thus be seen as a threat. However this may not always be so and the researcher may not necessary be seen as a threat. For instance in one particular survey the researcher was perceived to be the Deputy Minister trying to ascertain the details of the misery of the poor first hand and hoped that some relief would soon be provided (Socio-economic survey of Hyderabad and Secunderabad City Area, by the Indian Institute of Economics, Hyderabad, 1957).

Where the researcher makes efforts to gain cooperation by trying to effectively ward off negative perceptions, the researcher should also make efforts to ward of *false perceptions*. Consider another study where the research team was escorted by a health worker in a jeep – seen as a symbol of governmental authority. The health worker informed the team that "the team would be received with the reverence villagers habitually extend to government functionaries" (Balakrishnan, R., '93). It is then the research teams responsibility to clarify their identities. It then amounts to the need for effective informed consent, addressing this issue.

Privacy Anonymity and Confidentiality

Privacy, Anonymity and Confidentiality are indispensable rights of the participants. These are essential for the protection of the participants from the harmful and the undesirable consequences of research. Information collected from the participants should be disseminated in a form that does not lead to revealing of the identities of the participants. *Protection of identities does not simply mean using pseudo names.* A study can violate these rights even without revealing names. What if the study identifies to some extent, the research setting, and through community maps, marks the houses of participants and associates them with forms of sexual behaviour such as "extra marital affair"? One can only imagine the potential of harm that can be thus caused to the participants. One can even anticipate its potential affect on the credibility of social science research.

Privacy is essential at the time of data collection, though a difficult prospect in India. However, the concept of privacy itself in not new to our country. In 1958, a study conducted by the Bharat Seva Samaj in the slums of Old Delhi, gave specific instructions to make sure that no crowd gathered around the participants at the time of the interview. Where the concept is not new, why then the practice? Moreover there have been recent instances of studies that have felt the strong need for ensuring privacy at the time of data collection.

Consider a study which looked into induced abortions in a rural community, one investigator conducted the actual interview, while other family members were engaged in dummy interviews (Ganatra, B. R. et. al, 1994 - 96). It should be noted here that in the same study the right to autonomy was also taken care of and women were not given incentives or coerced into participation. Moreover, They were also provided with back-up medical services and counselling and information on family planning options.

The importance of these rights and the recognition of the potential of harm that information collected through studies and surveys can be judged by the fact that the Census Act, 1948, clearly lays down that data collected in the household schedule and individual slips are confidential and aggregate not identifiable data is not.

Moreover, a number of researchers see the practice of Privacy, Anonymity and Confidentiality essential even for trust building. For instance in a study on sex workers in Calcutta, the participants were asked to fill up self-monitoring cards giving relevant details, but no personal identification. They were then asked to put all the cards together. The cards were mixed and the participants were asked to identify and pick up their individual cards. All of them failed to do so (Bhattacharya and Senapati, 1994). This ensured Privacy, Anonymity and Confidentiality made the participants confident to participate in the study, and went on to reveal very intimate and personal information. In an another instance, in a study of gynaecological morbidity, the researchers reveal that the women were more willing to reveal gynaecological problems since they were confident about the confidentiality ensured (Koenig, M, et al).

Moreover, it is not always necessary that the participants would not want to be identified. Such was the case in T. N. Madan's study on Kashmir Pandits. T. N. Madan, himself a Pandit, was very well accepted by the community. This gave him access to information on disputes and other very confidential information, which he earlier did not have access to. He was also asked to intervene in family disputes. He then found it ethically unacceptable to identify the name of the village, even as a pseudonym (doubting the effectiveness of using one), since the information he thus collected was on the basis of the trust the participants placed in him as a result of him being identified as being one of them. Things were made simple for Prof. Madan when the participants of the study themselves insisted that the identity of the village need not be disguised at all (Barnes, J. A., 1977). However, it is a recognised fact that total and absolute Privacy, Anonymity and Confidentiality cannot be given to the participants, for the simple reason that information is commonly shared with other researchers. This then brings us to the issue of ethics in data sharing and dissemination.

Data Sharing and Reporting and Publication of Research

Data and information is often shared amongst researchers. While this itself is a good practice, the information thus shared should be non-identifiable, and in consonance to the rights of the participants. It is necessary that the participants be informed about this aspect of research, since rights of Privacy, Anonymity and Confidentiality and Sharing of data are obviously linked.

Often the participants themselves may be curious to know the responses of others and may expect the researcher to share such data. The researcher should decline such a request, but also expressly reveal that the information would be shared with a selected few. As the word spreads, participants would stop asking questions as a result in establishing trust and confidence in the researcher. (Bhatnagar, 1981)

Sharing of data should not be a condition for gaining access since even though the gatekeepers often assert that they have the interests of prospective participants at heart, it need not necessarily always be so. A similar approach should be taken wherever the participants or the study population is accessed via a gatekeeper. Where the research is sponsored by the gatekeepers themselves, the anonymity of the participants is very essential, including the names of those who have declined participation. Revealing of identifiable data to the gatekeepers can lead to extensive harm to the participants. Even where data is required to improve the conditions within say a prison, it can be argued that this too requires only non-identifiable facts.

Fabrication, falsifications of data, plagiarism are other very wide spread ethical violations, and should not be indulged in at any stage of research. The potential for the fabrication of data is high at the time of data collection, when the researchers may themselves be tempted to fabricate and falsify data. However, at times even the participants may insist on entering data, other than the one they might have revealed to the researcher earlier. Plagiarism also extends to the data and writings of juniors and students, not just amongst researchers. Where due credit is not given to the substantial inputs of the juniors and students, this would then amount to plagiarism and exploitation.

One of the important causes of plagiarism in our country is that the researchers are not good at reporting and publishing of their researches. Researchers sometime make presentations of their findings in meetings but do not publish them. There is so much good research and significant data that remain unpublished and consequently a lot of research is conducted on the same issue repeatedly. Further, poor dissemination or not disseminating the research at all leads to *defeating one of the most important purposes of undertaking research, that of increasing knowledge for the benefit and betterment of society and for the increasing of information on issues that are crucial for the betterment of the people. What use is collected and stored knowledge, if it is not published and disseminated?*

However, publication of researches carries with it inherent ethical complications. From publication of poor quality research, which has its own harms, to not effectively camouflaging the study. Identification of participants through such reports can lead to extensive harm not just to he participants of research but also to the researchers themselves as well as the entire research endeavour. Implications or the impact of a study may not necessarily be immediate. It may be long after the study is completed.

One way of handling this to take the results of the study and the reports back to the participants - a form of an extended debriefing. This could however to some extent be seen as a threat to the academic freedom of the researcher (Michael Useem and Gary Marx). But, where the participant compromises on very strong objections to certain information, he is anyway ethically obliged to either remove it or camouflage it more effectively without distorting the data.

The Politics of Social Science Research

The ethics of social science research cannot be taken into consideration without some reference to the politics of social science research. This is simply because the politics of research inevitably impinge upon the ethics of research. The interests of the powerful or the vested interests can direct research right from the selection of the research topic or agenda to the publication of research results or rather their non-publication. The political and administrative groups are known to act as pressure groups to that affect and even change the outcome of the research (Jaganadhan, 1967).

As mentioned earlier control over research funds may determine the direction of research and thus what is researched and what is not may not necessarily be directed by a strongly felt need to research these areas. On the contrary it might eventually lead to the neglect of research into areas and issues that desperately need looking into. The harm however is not just caused to the society, but also the researchers themselves. They might eventually end up becoming mere tools in the hands of vested interests (Srinivas, 1971).

Going beyond setting of agendas of research, vested interests can obviously influence almost all other aspects of research. Let us consider research findings. Researchers may be forced to present a different reality than the actual. One can only imagine the "efforts" that can go into presenting such a picture, which can be anything fabrication of data or "laundering" and can be indulged in by anyone in the hierarchy, from the junior most research investigators to their more powerful bosses. For instance, a study that may be a part of a larger group of studies reveals results that may not be in tune to the results of the rest of the studies. Tuning or adjustment is what can be then done (Srinivas, 1987). Or consider the study cited earlier by T. N. Madan, where a government anthropologist was asked to change the findings of a study to have a particular community declared a scheduled tribe. The implications can be tremendous.

There is however the other side too. The more powerful, the controllers of money should not always be seen as tyrants. They are not ignorant of the interests of the society and the participants. It is when interests diverge or differ, do conflicts arise. And when these differences impinge on matters related to ethics in social science research, it then becomes difficult for researchers to uphold their own rights and rights of the participants.[4]

Conclusion

Unethical research not only can have an obvious impact on the participants of the study. However going further, it can also affect the credibility of the social science discipline. This in the long run can lead to crippling or stagnation of institutions, researchers or the discipline itself. It can also lead to the creation of a false public knowledge or set of facts, leading to misguided policies.

Confirming to ethics in research may not be easy. Dynamics and perspectives differ. Each situation has its own complexities and ways to handle. Influencing forces too exert their pulls and pressures. It may be argued it may not thus be the responsibility of a singular researcher. It is that of all those associated with the entire research endeavour.

However, it is we researchers who form the most crucial link between the participants the society, those funding research and those who use research results to formulate policies. It is not just our duty to protect our integrity and autonomy and to protect the participants of research, where the threat exists, but it is also our right, our right to academic freedom. If we give up our rights and duties, to confirm to ethics in research, the credibility of social science research and the belief in the entire system, of inputs i.e. in terms of the research endeavour itself, and the outputs in terms of data or policies, and thus benefits, is threatened. It is our duty to go into a critical self-reflection of our work our practices and our goals.

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[4] This should however not become an excuse to diverge from ethics by researchers.

There are no magical formulas to the ethical dilemmas in Social Science Research. However, what can be done is to become aware and identify and effectively raise, debate and attempt to solve these issues. It should never be forgotten that *while perspectives towards ethics and dynamics in research may vary, the potential of harm of unethical research remains.*

References

Balakrishnan, R., State Sponsored Health Care in Rural Uttar Pradesh: Grass Root Encounters of a Survey Researcher, Sociological Bulletin, 45(1), March'93

Barnes, J.A., The Ethics of Inquiry in Social Sciences, 1977

Bharat Seva Samaj, Slums of Old Delhi, Report of the Socio-Economic Survey of the Slum Dwellers of Old Delhi City, *1958*

Bhatacharya, S., and Senapati.,S., Sexual Practices of the sex Workers in a Red Light Area of Calcutta,.Indian Journal of Social Work, vol. LV, No. 4, 1994

Bhatnagar, O.P., Research Methods and Measurements in Behavioral Sciences, 1981

Bose, A., Population of India: 1991 Census Results and Methodology, 1991

Chatterjee, B. B., Methodology of Social Science Research, Edt. Sugata Dasgupta, 1967

Cook, S., Research Methods, Edt. L. H. Kidder

Das, V. et. al, Scientific and Political Representations: The Cholera Vaccine in India, Centre for Development Economics, "Social Science and Immunisation Country Study: India, Working Paper 5.

Ganatra, B. R., Hirve, S. S., Walawalkar, L., Garda, L., and Rao,. V. N., "Induced Abortions in a rural Community in Western Maharashtra: Prevalence and Patterns, 1994 - -96

Hershfield, et.al, Fieldwork in Rural Areas, Social Research in Developing Countires, Edt. Bulmer and Warwick.

Jaganadhan, in Methodology of Social Science Research Edt. Sugata Dasgupta, 1967

Jindel, R., Culture of a Sacred Town – A Sociological Study of Nathdwara, 1975

Khanna, R., Dilemmas and Conflicts in Clinical Research in Women's Health – A Case Study of Sarthi, Medico Friend Circle Bulletin, Jan-Feb 1996

Koenig, M., Jeeebhoy, S., Singh, S., Sridhar, S., Undertaking Community based research on the prevalence of Gynecological Morbidity: lessons from India, Paper presented at the IUSSP Seminar on innovative Approaches to the Assessment of Reproductive Health, Manila, 1996

Kothari, S., and Joshi, K., A Comparative Study of Delinquents and non-Delinquents with regard to some Personality Characteristics, Indian Journal of Psychology, 1992 67(3&4)

Krishna, K. P., Status of Psychological Researches in India: Issues and Perspectives, Psychological Studies, 1991, Vol. 36, No. 1

Lee, R., Doing Research on Sensitive Topics, 1993

Madan, T. N., Political Pressures and Ethical Constraints Upon Indian Sociologists, in Ethics, Politics and Social Research, Edt. Gideon Sjoberg, 1967

Pelto, P., Qualitative Data - Gathering for Reproductive Health Research, John Hopkins University Working Paper

Singh, Y., Relevant Sociology: Some Conceptual Issues and the Indian Situation, Relevance in Sociological Research, Edt. S. L. Doshi, 1991

Srinivas, M. N., Dominant Caste and Other Essays, 1987

Srinivas, M. N., Modernization – A few queries,; Essays on modernization of Underdeveloped Societies, Vol. I, Edt. A. R. Desai

Srinivas, M. N., Social Change in Modern India, 1972

Sutton, R. and Schurman, S., On studying Emotionally Hot Topics: Lessons from an Investigation Of organizational Death, Clinical Methods.

The Indian Institute of Economics, Hyderabad, Socio-Economic Survey of Hyderabad and Secunderabad City Area, 1957

Useem, M. and Marx, G., Ethical Dilemmas and Political Consideration. An Introduction to Social Research, Volume I, of Handbook of Social Science Methods, Edt. Robert Smith, 1983.

Varma, Baidyanath, Prospects of Social Research in India, A Guide to field study, Edt. Shankar Sen Gupta, 1965

Vidyarthi, L. P., Upadhaya, V. S., Development of Researchers in Anthropology in India, Bihar – A Case Study, 1991

The paper uses "Ethics in Social Sciences and Health Research – A Draft Code of Conduct", Economic and Political Weekly, March 18 2000, as a the main reference line

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Tejal Barai
CEHAT
Mumbai

BACKGROUND PAPER: 7
Draft Not To Be Quoted

What good will come about from your research?

Some Reflections on the Ethics of Doing Ethnographic Research on Health[1]

Lester Coutinho [2]

Introduction

During the last several years of doing research on various issues of health, informants have frequently posed the following question to me - what good will come about from your research - or variations of this, questioning how the research would benefit them. Colleagues, who have worked with me, especially junior research staff; have often returned from the field disturbed by this question. The question becomes particularly disturbing when it is asked by persons from underprivileged sections of society who do not have access to adequate health care, but can be equally challenging when asked by those who may have access to good health care, but are simply cynical about research of this kind. So on the one hand there is *hope* of the research becoming a resource to the community, and on the other hand is the *hopelessness* of any kind of research. As students it was perhaps easier to answer this question, but as professional researchers we know that our attempts to provide grand explanations of how the outcomes of this research would feed into policy and plans or make governments more sensitive to the needs of the people does sound hollow.

One way of answering the question posed in the title of this paper is to offer answers of the kind that I have suggested above. An alternative way of answering this question is to read into the question whether or not the research in terms of it being a process includes those elements that would allow for the possibility of doing good (which definitely implies the impossibility of doing harm, but not just that).[3] Hence, the popular phrase 'doing good research' is to my mind inclusive of two dimensions - one points to the

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[1] This is a draft paper, and hence does not include proper referencing and acknowledgements. Kindly do not cite.

[2] The author is a Researcher at the Health Policy Research Unit of the Institute of Economic Growth, Delhi. Comments and suggestions may be sent to the author at lester@vsnl.com.

[3] I must point out here that possibility and intentionality are not synonymous. The possibility of doing good is to be distinguished from the intention of doing good. The former emphasises the practices and processes (inherent to the nature of the research as a whole) while the latter points only towards desire. Of course, unintended outcomes cannot be attributed to either lack of intentionality or possibility.

process and the other to the outcomes. I shall try to examine this in this paper, why the two can not be discordant. I shall not treat the subject as a classical philosophical debate on ends and means, but drawing on my own disciplinary strengths of sociology and anthropology, try to make research itself the object of ethnographic gaze, or engage in the reflexive gaze so as to allow for a unpacking some key concepts. I shall focus on three key issues, upon which much of the recent debates[4] on ethics of social science research, on health are hinged. In this paper, I propose to examine informed consent, confidentiality and social justice not just as ethical concepts but as practices within the practice of doing ethnographic research. The thread through which I attempt to weave these three issues in this paper, is the overarching question of this paper, viz. under what conditions does ethnographic research have the possibility of doing good? Informed consent, confidentiality and social justice are intrinsic to the practice of doing research. The paper argues that unless these inform both the constitution of the research object (including research questions and research design) and the research process (methodology and analysis), ethical considerations will be rendered as mere external appendages that at best may explain but do not inform and are not informed by the practice of doing research.

Ethnographic practice in health research

Before proceeding to examine these issues, in order to locate what follows, I would like to briefly discuss some general concerns of health research, especially ethnographic research, which this paper is centrally concerned about. Health research as whole is a contentious field, not only because it involves various social sciences, but more importantly because it is carried out it in the shadow of medicine, science and bio-technology which are based in far more universalistic discourses. While there is no denying the struggle for disciplinary hegemony between various social science disciplines, we have to also acknowledge similar tensions between the social and medical sciences (Johansson 1996). Besides bearing the responsibility of advancing knowledge, health research also carries with it the responsibility of producing *useful knowledge*. However, this has at times entailed assuming the social and cultural context of health issues as merely of significance for negotiating the delivery of medical science and its practices (mostly western biomedicine). In the specific context of medical anthropology, Scheper-Hughes (1990) has argued for a need to shift away from *clinical* medical anthropology' to *critical* medical anthropology because the former does not call into question the materialist premises of biomedicine, nor does it make any epistemic breaks

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[4] At the present moment one of the debates is about a report produced by the Almora based NGO Sahayog. The human rights concerns notwithstanding, the report raises concerns of confidentiality and informed consent not only in the manner in which the report has been prepared, but also with regard to its research methodology. Ethnographic research, has become fashionable (perhaps thanks to the demands of donor agencies), resulting in the watering down of methodological issues and the lack of application of rigorous theory and analysis. Unproblematised descriptive and narrative data leading to simplistic analysis cannot be passed off as ethnographic or qualitative research, as it is known in the market research sector.

from scientific medicine (as did social anthropology from the colonial world and its hegemony).

Ethnographic research (sociological or anthropological) on health is meant to focus on the *ethnomedical*, the social, cultural, and political dimensions of health issues rather than positivist biomedical scientific paradigms. Even in the Indian context we have begun noticing an increasing tendency to 'reduce the complexity and richness of anthropological knowledge to a few reified concepts' (Scheper-Hughes 1990). I have briefly discussed what is expected of ethnographic health research, and its increasing uncritical shift towards biomedical scientific paradigms as laying the ground to discuss how issues of confidentiality and informed consent cannot be framed within the concerns of biomedical scientific practice. With an increasing amount of health research being carried out by organisations that are also involved in doing health interventions, which are largely biomedical in nature, or by social scientists who uncritically accept the biomedical model of health (and hence have a stable and universal theory of disease, patient-user and doctor-provider as opposed to a theory that is local, specific and dynamic), there is also the tendency to frame confidentiality and consent primarily in terms of the doctor-patient relationship. This is itself embedded with a western biomedical scientific discourse. In what follows, I shall try to examine why, and perhaps how, we may conceptualise these ethical issues outside of a biomedical scientific discourse, because only then will health research itself be able to make an epistemic break from biomedical science and positivist science. This exercise is necessary (even though tentative and preliminary) if we are to avoid adopting a code of ethics for social science research that is to be distinct from other (especially biomedical) codes of ethics, so that our practices of research itself are distinct from that of other disciplines where health is also the object of research.

Finally, I would like to emphasise that ethnographic research is premised upon the need for 'thick descriptions', which can only be obtained through a reasonably prolonged and sustained engagement with the object of research. It is this process which produces relationships of trust, and affords in-depth insights. The increasing use of 'qualitative techniques' for rapid research is welcome, but is fraught with the risk of mistaking the tree for the forest. The ethical considerations of confidentiality and informed consent discussed below are specific to health as an object of research as constituted within the practice of doing ethnographic research based in anthropological /sociological practice and theory.

Confidentiality as social relationship

Following the classical pedagogy of teaching applied ethics, I would like to commence the section with a case from my own experience. During the fieldwork for gathering information on the 'immunisation practices' in Surat district, a colleague learned from some ANMs that instead of administering 0.5 ml of the DPT vaccine, they administered only 0.25 ml. Their reason for doing so was the fear that often children developed fever after being administered this vaccine, resulting in mothers (and other care takers) concluding that the vaccine caused fever and hence not bringing the child for subsequent doses of the vaccine. Also, the ANMs pointed out that they did not have adequate stocks of paracetamol tablets to treat the fever. From their local experience they had concluded that giving a 'lesser' dosage reduced the 'risk' of the child getting fever, and this ensured that the mother returned for other vaccines. Of course, their concern for ensuring that the child returned was informed by the target-driven approach.

The field investigator had over a period of almost six months developed a relationship of trust with the ANMs and had been living with them and travelling with them as they visited various villages. They no longer felt that they were being observed for evaluation and hence had begun feeling more secure in sharing information with the researcher. The matter was brought to the attention of senior researchers and the principal investigators. At stake were two conflicting issues; one of confidentiality (towards the ANMs who had informed us of the practice) and secondly of beneficence (towards the children who faced risk of not developing immunity due to this practice). Of concern was also the fact that if the matter was brought to the attention of the concerned health authorities, the ANMs might be selectively targeted for 'punishment' and would also loose esteem among colleagues who might also be engaging in similar practices. We ultimately, chose to instruct those ANMs who had informed us about such vaccination practices that this was a wrong practice, which they should discontinue and explained to them the greater risk the children faced if they continued such practices. In the final report and various other papers and dissemination workshops this practice was discussed but neither names of the ANMs, nor the PHCs were disclosed though the district was identified.

The case identified is not unique, and similar and more challenging issues have emerged in doing research on issues such as illicit drug use, sexual health, doctor-patient relationship and use of pharmaceutical products. In each of these cases it is not enough to record 'wrong practices'. The challenge is to understand and explain why and how these practices are produced. The very object of research demands an approach/a methodology that subsumes confidentiality, and this informs what we may seek to know and how we may come to know it. The increasing use of covert techniques, like the simulated client method (as in a recent study on quality of care provided by doctors treating persons STDs) raises the ethical question of not just consent (of the provider), but also of confidentiality which is to be understood as that which emerges from a relationship of trust. Confidentiality understood as a relationship entails that it is shared by, two or more individuals. And because it is a relationship, it has specific contexts within which it is meaningful. Similar knowledge may exist outside such a relationship (of confidentiality), the relationship within which it is produced, and the wider social relationships it produces are different.

To further this idea of confidentiality as embedded in social relationships, I shall draw upon the idea of 'poisonous knowledge' (Veena Das). The knowledge of, an individual's illness may be shared by a family and or some members of the family. That knowledge within the context of specific relationships enjoys a relationship of confidentiality and hence a particular meaningfulness. Outside that relationship, the information maybe constituted as 'poisonous knowledge' as it allows for not only altering the relationship to that particular information, but also of individuals (who share that knowledge) to each other. As social scientists doing (ethnographic) research on health issues like those listed above, we must at the outset attempt to imagine and understand within what contexts and relationships is a particular information confidential, and how availability of that information in other contexts may alter the meaning of that information, and the relationship between those who share this information. Confidentiality is hence to be constantly produced between individuals and collectivities that share particular universes of meanings. The fact of a particular individual suffering a stigmatising health condition is meaningful in one particular way within the universe of meanings shared by the researcher and the informant. Therein lies the relationship of confidentiality. The same information outside that particular relationship and universe of meanings must 'transform' itself to be meaningful within another kind of relationship embedded in a different universe of meanings and context, so that the meaning it shares within one context does not become poisonous (danger/harm producing) to its earlier context. Hence information about an individuals illness or a particular health practice must be divested of those aspects which may constitute it as poisonous knowledge when it is to be shared within those who share a relationship as health researchers, policy makers, or law enforcing agencies. The information can only be shared in other contexts, as in a research paper, so as to make it meaningful to the intended audience, which may be community of researchers or health administrators and policy makers, and hence may be represented in a manner that does not harm the relationship (context and universe of shared meanings) within which it was first gathered. I shall not labour the point further, but shift to understanding how confidentiality in social science research is to be understood as distinct from confidentiality in the doctor-patient relationship, and biomedical research. I am not suggesting that the two are antithetical to each other, but the nuances are significantly different.

It is unfortunate that often parallels are drawn between the relationship of doctors and their patients and between social scientists and their informants. Even though confidentiality is instrumental to both, Robinson (1991) has argued that the role of confidentiality in social science research is more significant than in medical context because of the expectations of the participants in the particular relationships. In this sense confidentiality of clinical situations should be distinguished from confidentiality in research situations. Unlike, clinical situations the initiator of the relationship (encounter) is the researcher and not the informant, as opposed to the client being the initiator in the clinical encounter. In each of cases the purpose of confidentiality 'is to protect the patient and informant and through that protection offer the possibility of effective practice of medicine and social science respectively. In the clinical encounter confidentiality is primarily (though not exclusively) aimed at protecting the 'physical person', as opposed to social research where the primary aim to protect the 'social person' (Cassell 1982). This distinction between the *social body* and the *clinical (biological body*) and the distinct nature of harm that can be produced is crucial if we understand the varied contexts of confidentiality. According to Robinson (1991) the social body is faced with graver danger because it's subject matter is related with a wider audience.

Further, unlike clinicians and medical researchers, social scientists are not formally or legally bound by a unified code of ethics that informs their practice. Confidentiality in social science research remains a loosely defined term. Even in the British Sociological

Association Code of Practice, the researcher is only required to 'make clear the nature of confidentiality offered' and not give guarantee of confidentiality that may not be fulfilled. On these grounds social science research may be criticised for not having a universal or *a priori* sense of confidentiality. Since knowledge produced through social science research recognises its *situatedness*, the character of the ethical norms for confidentiality is equally situated. This pluralist position should not be mistaken for a relativist ethical stance. Since, the researcher is the initiator of the relationship, he/she has the obligation of understanding the particular demands of the informant's particular expectations. Also, 'the situatedness of confidentiality may arise out of the particular kinds of social research' (Robinson 1991). The kind of confidentiality negotiated through ethnographic research may be very different from that negotiated through survey research. The nature of knowledge produced by, and the scale and focus of these different research methods allows for different kinds of negotiations and relationships of confidentiality.

Finally, unlike the clinical encounter, the context in which social science research takes place is crucial to interpreting the nature of confidentiality. At one level this requires a distinction between what is (perceive to be) private and what is public information (Robinson 1991). At another level, we need to distinguish between collective good (harm) and individual good (harm), while recognising that there may be disagreement as to what constitutes collective good, or who represents collective good.[5] Also, often confidentiality has been weighed in terms of individual interest versus public health interest. There is as much a public health interest as an individual interest in fostering what Bayen and Gostin (1997) have described as a 'regime of confidentiality'. However, this does not mean that there are no limits to confidentiality. In weighing the pro and cons of confidentiality the single most important principle to be born in mind is *not* the diffused sense of individual interest versus public interest, but the assessment of the real (situated) danger/risk posed to various individuals in diverse contexts. Even though not all harm can be anticipated, unintended outcomes effected by the knowledge produced may inform the formation of new kinds of social alliance. Confidentiality is not an end in itself. It is negotiable variously in diverse contexts but aims for the possibility of doing good and the impossibility of doing harm. This situated approach also recognises that not all individuals (informants) are equal and hence the possibility of doing good (no harm) would be relative to the degree of vulnerability and risk faced by various groups.

The Social Production Informed Consent

The key question within the larger debate on informed consent is whether patients should influence medical decisions. Here we must at the outset make a distinction between informed consent for normal therapeutic procedures, informed consent in the context of new medical technologies (for e.g. new drugs, vaccines or surgical procedures), informed consent for diagnostic procedures such as HIV testing, informed consent for social

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[5] Once again in the case of Sahayog's report we are faced with the dilemma as to who may represent the collective good in relation to the disclosure of certain kinds of information. This would depend very much on whether the information gathered can be constituted as private information or public information.

science health research. There have been two broad orientations that have governed discussions on the issue of consent. On the one hand there is the framework where the autonomy of the patient is subordinated to his well being (and at times also the well being of the public). And on the other there has been the framework wherein respect for the patient and the exercise of his autonomy has been primary. The ethic of the former is geared towards outcomes, while the ethic of the latter is geared towards the procedure of informed consent.

In medical ethics there has been much uncertainty and confusion about not what constitutes informed consent, but more importantly how are we are to obtain informed consent, especially in the context of non-literate societies, and in cultures where the doctor-patient relationship is primarily one of total trust, or like the relationship between researcher and informant is also one of power and hierarchy. One of the key questions to pose, in order that we may arrive at a more practical and useful understanding of the concept is 'what purpose(s) does informed consent serve'. It certainly cannot be argued that informed consent is in an end in itself, but is a means towards other ends. One of the most important arguments in favour of informed consent is that it is meant to protect subjects from possible harm (thus creating or enhancing the scope of the possibility to do good). Informed consent in the context of social research cannot be understood in the same way as in a case of diagnostic testing for infectious and communicable diseases (e.g. HIV), or invasive surgery, or the trial of an experimental vaccine or new medical technology. The nature and degree of harm in these various cases varies. While the patient has the right to understand what are the benefits and risks of a particular medical procedure, so also does an informant have the right to know to what ends the information given will be used, the nature or risk and vulnerability he may encounter having given the required information. Informed consent primarily is about creating the possibility of a relationship not only between the social researcher who initiates the encounter with the informant, but also between the informant and the research objectives and final outcomes. While it is true that data, especially ethnographic data may be examined and analysed in a manner not anticipated at the outset of the research, the informant needs to be made aware of this possibility.

The procedure for obtaining informed consent has been a much- debated issue in bio-ethics. The printed form is common in most countries, but it has become increasingly evident that such procedures are not effective in communicating the risks and benefits of a particular medical procedure or social research process. This aspect becomes even more crucial when social science researches issues that are likely to have implications not just to individual *social body* but also the body politic (or specific groups like women, children, migrants, sex workers, etc.).

The criticism against written information to obtain consent becomes particularly relevant in non-literate societies, as is the case in large parts of India and other developing countries. Studies have shown that patients read and sign these printed forms but are later unable to recall what they read and whether they have read it at all (see Riecken and Ravich 1982). As a procedure for obtaining consent, the printed form has also been criticised for being a token action to fulfil the legal requirements, rather than to communicate information to the concerned individual (Lewis 1982). A more significant criticism against the printed form as a procedure for obtaining informed consent is that the language (medical terms) used cannot be comprehended by even educated persons. Alternatives like the use of video-tapes, brochures, group discussion, professional counselling) have been suggested, but unfortunately we do not have much information based on research on the effectiveness of such procedures. In the case of the anti-fertility vaccine trials in India, the doctors engaged in the trial claimed that they had used a video-tape to inform and explain to women the benefits, risks and procedures to be followed in the trial before obtaining their signatures on printed forms. However, this could not be verified by the researchers (see Viswanath and Kirbat 1997) as neither was the video tape ever made available under various pretexts, nor were they able to confirm this with the women who participated in the trial. The key issue here is that it is not adequate to have a printed form for obtaining consent, and there needs to be serious application of mind to determine what procedures for obtaining consent would be effective and relevant in diverse situations. Even if consent is assumed through a particular relationship that the researcher (especially ethnographers) may share with individuals or a community, these processes need to be adequately fore-grounded in the research.

The ethical concerns of confidentiality cannot be disassociated from those of informed consent. Both are embedded within social relationships, and are practices that are con-terminus to each other. Informed consent like confidentiality is to be situated in relation to the object of research; both inform and are informed by the object of research, the objectives of research, the research methods used, and the situated-ness of the ethnographer-informant relationship.

Towards an ethics of social justice in health research

Meaning is form of politics, and the processes of knowing are also informed by politics. As stated at the outset of the paper, social science research on issues of health are inherently intended towards producing useful knowledge, but we also need to be critically aware of the corollary question: whom would such knowledge be useful to? Most codes of ethics pay much attention to respect for autonomy, but pay much less emphasis on social justice issues. In the Indian context and that of other developing countries, we have to take into cognisance as an ethical issue the serious inequalities in access to adequate health care services. What aspects of health care are researched are not always informed by social justice issues, but more often by agendas set by funding agencies, state policies (which may themselves be skewed towards elite) and international organisations whose agenda may be informed by interests of developed countries, multinational pharmaceutical companies, and other stake holders in the international health sector.

Social justice may be described as a contested domain, and yet we have adequate evidence from previous social science research on the nature of inequalities and how these produce health and illness. Taking cue from Klienman and Das, we need to recognise the nature of social suffering in relation to issues of health, especially public health. Illnesses that enter the universe of the clinic are equally a reflection of the 'tragic experiences of the world' (Scheper-Hughes 1990). This perhaps calls for questioning of what is social in social science research on health. Is the method to be social scientific, or are the questions and the problems addressed to be primarily considered social.

If social science research on health is to become relevant to society, to individuals and collectivities whose social suffering it seeks to represent, it has to strive to produce the counter-culture to hegemonic practices of conventional science and medicine, to the policies of state and international agencies, to ruthless market forces personified through pharmaceutical companies, social science research needs to relate to social justice not as moral issue, but as an ethical issue that informs its own research agenda and practices.

In lieu of conclusions

Through the terrain I have so far traversed in this paper, I have primarily tried to address the question, which forms the title of this paper. At the outset I only partly prolematised the situated-ness of this question, i.e. who is asking this question. Perhaps, through an ethic informed by concerns of social justice, we may be able to nuance what 'good' would mean to various sections of society. I am reminded of the question being asked of me by an woman from an upper class household in Delhi, and also being asked the same question by a woman from a slum community in Delhi. Both suffered from chronic pain, but I'd like to believe that their different social positioning rendered different meaning to that question. In the case of the upper class woman our research on management of chronic pain would have no consequence to her *dard* (physical pain) as she had tried various therapies. In the case of the lower class woman, her *dard* (physical pain*), dukh* (personal pain*)* and *gam* (social pain) could not be separated from each other, and hence what good would come about from our research even if it helped her treat her physical pain. Herein lies the challenge of doing social science (ethnographic) research on health issues - to foreground the social.

I like to (tentatively) conclude this paper, by setting forth yet another question: how can ethnographic health research address the ethical issues discussed herein. Even at the risk of sounding overly protective of the discipline I practice, I dare to suggest that the answer to this lies in recognising the situated-ness of the object of research, the research questions, and the researcher.

Such a recognition would entail that ethnography should move towards self-reflexivity, where in the researcher recognises her/his moral subject-positioning, and equally that of the of the object of research. This also entails that besides producing an ethnography of the health issues itself, there is need to construct an ethnography of what is the particular (local) ethical framework which informs peoples' health concerns, how are larger ethical concerns informing their local concerns, and nature of the researcher's own ethical concerns. Any analysis of the research questions must be interwoven with these ethical narratives so that if health research is live up to the possibility of doing good, that ethical imperative can emerge in the confluence of recognising conflicting and intertwining ethical perspectives and moral positions. It may not be task of the researcher to do good, but in clarifying these issues through ethnographic practice, allows for the possibility of doing good, even though outcomes may not always be what they are intended to be.

This paper is incomplete. Please do not quote.

Mr. Lester Coutinho
The author is a Researcher at the Health Policy Research Unit of the Institute of Economic Growth, Delhi. Comments and suggestions may be sent to the author at lester@vsnl.com

National Meeting to Discuss

The Draft Code of Ethics
For Research in Social Sciences
And Social Science Research in Health

May 29-30, 2000
YMCA, Mumbai Central
Mumbai

Organised by
CEHAT
(Research Centre of Anusandhan Trust)
2nd Floor, BMC Bldg., 135 Military Road
Next to Lok Darshan, Marol, Andheri East
Mumbai 400 059. India
Tel: (91)(22) 851 9420, Fax: (91)(22) 850 5255
Email: cehat@vsnl.com

Information Material
SOME RELEVANT CODES OF ETHICS

The British Sociological Association
Statement of Ethical Practice

The British Sociological Association gratefully acknowledges the use made of the ethical codes produced by the American Sociological Association, the Association of Social Anthropologists of the Commonwealth and the Social Research Association.

Styles of sociological work are diverse and subject to change, not least because sociologists work within a wide variety of settings. Sociologists, in carrying out their work, inevitably face ethical, and sometimes legal, dilemmas, which arise out of competing obligations and conflicts of interest. The following statement aims to alert the members of the Association to issues that raise ethical concerns and to indicate potential problems and conflicts of interest that might arise in the course of their professional activities.

While they are not exhaustive, the statement points to a set of obligations to which members should normally adhere as principles for guiding their conduct. Departures from the principles should be the result of deliberation and not ignorance. The strength of this statement and its binding force rest ultimately on active discussion, reflection, and continued use by sociologists. In addition, the statement will help to communicate the professional position of sociologists to others, especially those involved in or affected by the activities of sociologists.

The statement is meant, primarily, to inform members' ethical judgements rather than to impose on them an external set of standards. The purpose is to make members aware of the ethical issues that may arise in their work, and to encourage them to educate themselves and their colleagues to behave ethically. The statement does not, therefore, provide a set of recipes for resolving ethical choices or dilemmas, but recognises that often it will be necessary to make such choices on the basis of principles and values, and the interests of those involved.

At its meeting in July 1994, the BSA Executive Committee approved a set of Rules for the Conduct of Enquiries into Complaints against BSA members under the auspices of this Statement, and also under the auspices of the BSA Guidelines on Professional Conduct. If you would like more details about the Rules, you should contact the BSA Office at the address/phone number given at the end of this statement.

Professional Integrity

Members should strive to maintain the integrity of sociological enquiry as a discipline, the freedom to research and study, and to publish and promote the results of sociological research. Members have a responsibility both to safeguard the proper interests of those involved in or affected by their work, and to report their findings accurately and truthfully. They need to consider the effects of their involvements and the consequences of their work or its misuse for those they study and other interested parties.

While recognising that training and skill are necessary to the conduct of social research, members should themselves recognise the boundaries of their professional competence. They should not accept work of a kind that they are not qualified to carry out. Members should satisfy themselves that the research they undertake is worthwhile and that the techniques proposed are appropriate. They should be clear about the limits of their detachment from and involvement in their areas of study.

Members should be careful not to claim an expertise in areas outside those that would be recognised academically as their true fields of expertise. Particularly in their relations with the media, members should have regard for the reputation of the discipline and refrain from offering expert commentaries in a form that would appear to give credence to material which as researchers they would regard as comprising inadequate or tendentious evidence.

Relations With And Responsibilities Towards Research Participants

Sociologists, when they carry out research, enter into personal and moral relationships with those they study, be they individuals, households, social groups or corporate entities. Although sociologists, like other researchers are committed to the advancement of knowledge, that goal does not, of itself, provide an entitlement to override the rights of others. Members must satisfy themselves that a study is necessary for the furtherance of knowledge before embarking upon it. Members should be aware that they have some responsibility for the use to which their research may be put. Discharging that responsibility may on occasion be difficult, especially in situations of social conflict, competing social interests or where there is unanticipated misuse of the research by third parties.

1. Relationships with research participants

Sociologists have a responsibility to ensure that the physical, social and psychological well-being of research participants is not adversely affected by the research. They should strive to protect the rights of those they study, their interests, sensitivities and privacy, while recognising the difficulty of balancing potentially conflicting interests. Because sociologists study the relatively powerless as well as those more powerful than themselves, research relationships are frequently characterised by disparities of power and status. Despite this, research relationships should be characterised, whenever possible, by trust. In some cases, where the public interest dictates otherwise and particularly where power is being abused, obligations of trust and protection may weigh less heavily. Nevertheless, these obligations should not be discarded lightly.

As far as possible sociological research should be based on the freely given informed consent of those studied. This implies a responsibility on the sociologist to explain as fully as possible, and in terms meaningful to participants, what the research is about, who is undertaking and financing it, why it is being undertaken, and how it is to be promoted.

Research participants should be aware of their right to refuse participation whenever and for whatever reason they wish. They should also not be under the impression that they are required to participate.

Research participants should understand how far they will be afforded anonymity and confidentiality and should be able to reject the use of data-gathering devices such as tape recorders and video cameras.

Where there is a likelihood that data may be shared with other researchers, the potential uses to which the data might be.put may need to be discussed with research participants.

When filming or recording for research purposes, sociologists should make clear to research participants the purpose of the filming or recording, and, as precisely as possible, to whom it will be communicated. Sociologists should be careful, on the one hand, not to give unrealistic guarantees of confidentiality and, on the other, not to permit communication of research films or records to audiences other than those to which the research participants have agreed.

It should also be borne in mind that in some research contexts, especially those involving field research, it may be necessary for the obtaining of consent to be regarded, not as a once-and-for-all prior event, but as a process, subject to renegotiation over time. In addition, particular care may need to be taken during periods of prolonged fieldwork where it is easy for research participants to forget that they are being studied.

In some situations access to a research setting is gained via a 'gatekeeper'. In these situations members should adhere to the principle of obtaining informed consent directly from the research participants to whom access is required, while at the same time taking account of the gatekeepers' interest. Since the relationship between the research participant and the gatekeeper will continue long after the sociologist has left the research setting, care should be taken not to inadvertently disturb that relationship unduly.

It is incumbent upon members to be aware of the possible consequences of their work. Wherever possible they should attempt to anticipate, and to guard against, consequences for research participants which can be predicted to be harmful. Members are not absolved from this responsibility by the consent given by research participants.

In many of its guises, social research intrudes into the lives of those studied. While some participants in sociological research may find the experience a positive and welcome one, for others, the experience may be disturbing. Even if not exposed to harm, those studied may feel wronged by aspects of the research process. This can be particularly so if they perceive apparent intrusions into their private and personal worlds, or where research gives rise to false hopes, uncalled for self-knowledge, or unnecessary anxiety. Members should consider carefully the possibility that the research experience may be a disturbing one and, normally, should attempt to minimise disturbance to those participating in research. It should be borne in mind that decisions made on the basis of research may have effects on individuals as members of a group, even if individual research participants are protected by confidentiality and anonymity.

Special care should be taken where research participants are particularly vulnerable by virtue of factors such as age, social status and powerlessness. Where research participants are ill or too young or too old to participate, proxies may need to be used in order to gather data. In these situations care should be taken not to intrude on the personal space of the person to whom the data ultimately refer, or to disturb the relationship between this person and the proxy. Where it can be inferred that the person about whom data are sought would object to supplying certain kinds of information, that material should not be sought from the proxy.

2. Covert Research

There are serious ethical dangers in the use of covert research but covert methods may avoid certain problems. For instance, difficulties arise when research participants change their behaviour because they know they are being studied. Researchers may also face problems when access to spheres of social life is closed to social scientists by powerful or secretive interests. However, covert methods violate the principles of informed consent and may invade the privacy of those being studied. Participant or non-participant observation in non-public spaces or experimental manipulation of research participants without their knowledge should be resorted to only where it is impossible to use other methods to obtain essential data. In such studies it is important to safeguard the anonymity of research participants. Ideally, where informed consent has not been obtained prior to the research it should be obtained post-hoc.

3. Anonymity, privacy and confidentiality

The anonymity and privacy of those who participate in the research process should be respected. Personal information concerning research participants should be kept confidential. In some cases it may be necessary to decide whether it is proper or appropriate even to record certain kinds of sensitive information.

Where possible, threats to the confidentiality and anonymity of research data should be anticipated by researchers. The identities and research records of those participating in research should be kept confidential whether or not an explicit pledge of confidentiality has been given. Appropriate measures should be taken to store research data in a secure manner. Members should have regard to their obligations under the Data Protection Act. Where appropriate and practicable, methods for preserving the privacy of data should be used. These may include the removal of identifiers, the use of pseudonyms and other technical means for breaking the link between data and identifiable individuals such as 'broadbanding' or micro-aggregation. Members should also take care to prevent data being published or released in a form which would permit the actual or potential identification of research participants. Potential informants and research participants, especially those possessing a combination of attributes which make them readily identifiable, may need to be reminded that it can be difficult to disguise their identity without introducing an unacceptably large measure of distortion into the data.

Guarantees of confidentiality and anonymity given to research participants must be honoured, unless there are clear and overriding reasons to do otherwise. Other people, such as colleagues, research staff or other employees, given access to the data must also be made aware of their obligations in this respect. By the same token, sociologists should respect the efforts taken by other researchers to maintain anonymity. Research data given in confidence do not enjoy legal privilege, that is they may be liable to subpoena by a court. Research participants may also need to be made aware that it may not be possible to avoid legal threats to the privacy of the data.

There may be less compelling grounds for extending guarantees of privacy or confidentiality to public organisations, collectivities, governments, officials or agencies than to individuals or small groups. Nevertheless, where guarantees have been given they should be honoured, unless there are clear and compelling reasons not to do so.

4. Relations With & Responsibilities Towards Sponsors And/Or Funders

During their research members should avoid, where they can, actions which may have deleterious consequences for sociologists who come after them or which might undermine the reputation of sociology as a discipline.

A common interest exists between sponsor, funder and sociologist as long as the aim of the social inquiry is to advance knowledge, although such knowledge may only be of limited benefit to the sponsor and the funder. That relationship is best served if the atmosphere is conducive to high professional standards. Members should attempt to ensure that sponsors and/or funders appreciate the obligations that sociologists have not only to them, but also to society at large, research participants and professional colleagues and the sociological community. The relationship between sponsors or funders and social researchers should be such as to enable social inquiry to be undertaken as objectively as possible. Research should be undertaken with a view to providing information or explanation rather than being constrained to reach particular conclusions or prescribe particular courses of action.

Clarifying obligations, roles and rights

Members should clarify in advance the respective obligations of funders and researchers where possible in the form of a written contract. They should refer the sponsor or funder to the relevant parts of the professional code to which they adhere. Members should also be careful not to promise or imply acceptance of conditions which are contrary to their professional ethics or competing commitments. Where some or all of those involved in the research are also acting as sponsors and/or funders of research the potential for conflict between the different roles and interests should also be made clear to them.

Members should also recognise their own general or specific obligations to the sponsors whether contractually defined or only the subject of informal and often unwritten agreements. They should be honest and candid about their qualifications and expertise, the limitations, advantages and disadvantages of the various methods of analysis and data, and acknowledge the necessity for discretion with confidential information obtained from sponsors. They should also try not to conceal factors which are likely to affect satisfactory conditions or the completion of a proposed research project or contract.

Pre-empting outcomes and negotiations about research

Members should not accept contractual conditions that are contingent upon a particular outcome or set of findings from a proposed inquiry. A conflict of obligations may also occur if the funder requires particular methods to be used.

Members should try to clarify, before signing the contract, that they are entitled to be able to disclose the source of their funds, its personnel, the aims of the institution, and the purposes of the project.

Members should also try to clarify their right to publish and spread the results of their research.

Members should be prepared to clarify with sponsors the methods of analysis to be used.

Guarding privileged information and negotiating problematic sponsorship

Members are frequently furnished with information by the funder who may legitimately require it to be kept confidential. Methods and procedures that have been utilised to produce published data should not, however, be kept confidential.

When negotiating sponsorships members should be aware of the requirements of the law with respect to the ownership of and rights of access to data.

In some political, social and cultural contexts some sources of funding and sponsorship may be contentious. Candour and frankness about the source of funding may create problems of access or co-operation for the social researcher but concealment may have serious consequences for colleagues, the discipline and research participants. The emphasis should be on maximum openness.

Where sponsors and funders also act directly or indirectly as gatekeepers and control access to participants, researchers should not devolve their responsibility to protect the participants' interests onto the gatekeeper. Members should be wary of inadvertently disturbing the relationship between participants and gatekeepers since that will continue long after the researcher has left.

Obligations to sponsors and/or Funders During the Research Process

Members have a responsibility to notify the sponsor and/or funder of any proposed departure from the terms of reference of the proposed change in the nature of the contracted research.

A research study should not be undertaken on the basis of resources known from the start to be inadequate, whether the work is of a sociological or inter-disciplinary kind.

When financial support or sponsorship has been accepted, members must make every reasonable effort to complete the proposed research on schedule, including reports to the funding source.

Members should be prepared to take comments from sponsors or funders or research participants.

Members should, wherever possible, spread their research findings.

Members should normally avoid restrictions on their freedom to publish or otherwise broadcast research findings.

American Sociological Association

ASA Code of Ethics

(Approved by ASA Membership in spring of 1997)

INTRODUCTION

The American Sociological Association's (ASA's) Code of Ethics sets forth the principles and ethical standards that underlie sociologists' professional responsibilities and conduct. These principles and standards should be used as guidelines when examining everyday professional activities. They constitute normative statements for sociologists and provide guidance on issues that sociologists may encounter in their professional work.

ASA's Code of Ethics consists of an Introduction, a Preamble, five General Principles, and specific Ethical Standards. This Code is also accompanied by the Rules and Procedures of the ASA Committee on Professional Ethics which describe the procedures for filing, investigating, and resolving complaints of unethical conduct.

The Preamble and General Principles of the Code are aspirational goals to guide sociologists toward the highest ideals of sociology. Although the Preamble and General Principles are not enforceable rules, they should be considered by sociologists in arriving at an ethical course of action and may be considered by ethics bodies in interpreting the Ethical Standards.

The Ethical Standards set forth enforceable rules for conduct by sociologists. Most of the Ethical Standards are written broadly in order to apply to sociologists in varied roles, and the application of an Ethical Standard may vary depending on the context. The Ethical Standards are not exhaustive. Any conduct that is not specifically addressed by this Code of Ethics is not necessarily ethical or unethical.

Membership in the ASA commits members to adhere to the ASA Code of Ethics and to the Policies and Procedures of the ASA Committee on Professional Ethics. Members are advised of this obligation upon joining the Association and that violations of the Code may lead to the imposition of sanctions, including termination of membership. ASA members subject to the Code of Ethics may be reviewed under these Ethical Standards only if the activity is part of or affects their work-related functions, or if the activity is sociological in nature. Personal activities having no connection to or effect on sociologists' performance of their professional roles are not subject to the Code of Ethics.

PREAMBLE

This Code of Ethics articulates a common set of values upon which sociologists build their professional and scientific work. The Code is intended to provide both the general principles and the rules to cover professional situations encountered by sociologists. It has as its primary goal the welfare and protection of the individuals and groups with whom sociologists work. It is the individual responsibility of each sociologist to aspire to the highest possible standards of conduct in research, teaching, practice, and service.

The development of a dynamic set of ethical standards for a sociologist's work-related conduct requires a personal commitment to a lifelong effort to act ethically; to encourage ethical behavior by students, supervisors, supervisees, employers, employees, and colleagues; and to consult with others as needed concerning ethical problems. Each sociologist supplements, but does not violate, the values and rules specified in the Code of Ethics based on guidance drawn from personal values, culture, and experience.

GENERAL PRINCIPLES

The following General Principles are aspirational and serve as a guide for sociologists in determining ethical courses of action in various contexts. They exemplify the highest ideals of professional conduct.

Principle A: Professional Competence

Sociologists strive to maintain the highest levels of competence in their work; they recognize the limitations of their expertise; and they undertake only those tasks for which they are qualified by education, training, or experience. They recognize the need for ongoing education in order to remain professionally competent; and they utilize the appropriate scientific, professional, technical, and administrative resources needed to ensure competence in their professional activities. They consult with other professionals when necessary for the benefit of their students, research participants, and clients.

Principle B: Integrity

Sociologists are honest, fair, and respectful of others in their professional activities—in research, teaching, practice, and service. Sociologists do not knowingly act in ways that jeopardize either their own or others' professional welfare. Sociologists conduct their affairs in ways that inspire trust and confidence; they do not knowingly make statements that are false, misleading, or deceptive.

Principle C: Professional and Scientific Responsibility

Sociologists adhere to the highest scientific and professional standards and accept responsibility for their work. Sociologists understand that they form a community and show respect for other sociologists even when they disagree on theoretical, methodological, or personal approaches to professional activities. Sociologists value the public trust in sociology and are concerned about their ethical behavior and that of other sociologists that might compromise that trust. While endeavoring always to be collegial, sociologists must never let the desire to be collegial outweigh their shared responsibility for ethical behavior. When appropriate, they consult with colleagues in order to prevent or avoid unethical conduct.

Principle D: Respect for People's Rights, Dignity, and Diversity

Sociologists respect the rights, dignity, and worth of all people. They strive to eliminate bias in their professional activities, and they do not tolerate any forms of discrimination based on age; gender; race; ethnicity; national origin; religion; sexual orientation; disability; health conditions; or marital, domestic, or parental status. They are sensitive to cultural, individual, and role differences in serving, teaching, and studying groups of people with distinctive characteristics. In all of their work-related activities, sociologists acknowledge the rights of others to hold values, attitudes, and opinions that differ from their own.

Principle E: Social Responsibility

Sociologists are aware of their professional and scientific responsibility to the communities and societies in which they live and work. They apply and make public their knowledge in order to contribute to the public good. When undertaking research, they strive to advance the science of sociology and to serve the public good.

American Sociological Association

ETHICAL STANDARDS

1. Professional and Scientific Standards

Sociologists adhere to the highest possible technical standards that are reasonable and responsible in their research, teaching, practice, and service activities. They rely on scientifically and professionally derived knowledge; act with honesty and integrity; and avoid untrue, deceptive, or undocumented statements in undertaking work-related functions or activities.

2. Competence

(a) Sociologists conduct research, teach, practice, and provide service only within the boundaries of their competence, based on their education, training, supervised experience, or appropriate professional experience.
(b) Sociologists conduct research, teach, practice, and provide service in new areas or involving new techniques only after they have taken reasonable steps to ensure the competence of their work in these areas.
(c) Sociologists who engage in research, teaching, practice, or service maintain awareness of current scientific and professional information in their fields of activity, and undertake continuing efforts to maintain competence in the skills they use.
(d) Sociologists refrain from undertaking an activity when their personal circumstances may interfere with their professional work or lead to harm for a student, supervisee, human subject, client, colleague, or other person to whom they have a scientific, teaching, consulting, or other professional obligation.

3. Representation and Misuse of Expertise

(a) In research, teaching, practice, service, or other situations where sociologists render professional judgments or present their expertise, they accurately and fairly represent their areas and degrees of expertise.
(b) Sociologists do not accept grants, contracts, consultation, or work assignments from individual or organizational clients or sponsors that appear likely to require violation of the standards in this Code of Ethics. Sociologists dissociate themselves from such activities when they discover a violation and are unable to achieve its correction.
(c) Because sociologists' scientific and professional judgments and actions may affect the lives of others, they are alert to and guard against personal, financial, social, organizational, or political factors that might lead to misuse of their knowledge, expertise, or influence.
(d) If sociologists learn of misuse or misrepresentation of their work, they take reasonable steps to correct or minimize the misuse or misrepresentation.

4. Delegation and Supervision

(a) Sociologists provide proper training and supervision to their students, supervisees, or employees and take reasonable steps to see that such persons perform services responsibly, competently, and ethically.

(b) Sociologists delegate to their students, supervisees, or employees only those responsibilities that such persons, based on their education, training, or experience, can reasonably be expected to perform either independently or with the level of supervision provided.

5. Non-discrimination

Sociologists do not engage in discrimination in their work based on age; gender; race; ethnicity; national origin; religion; sexual orientation; disability; health conditions; marital, domestic, or parental status; or any other applicable basis proscribed by law.

6. Non-exploitation

(a) Whether for personal, economic, or professional advantage, sociologists do not exploit persons over whom they have direct or indirect supervisory, evaluative, or other authority such as students, supervisees, employees, or research participants.

(b) Sociologists do not directly supervise or exercise evaluative authority over any person with whom they have a sexual relationship, including students, supervisees, employees, or research participants.

7. Harassment

Sociologists do not engage in harassment of any person, including students, supervisees, employees, or research participants. Harassment consists of a single intense and severe act or of multiple persistent or pervasive acts which are demeaning, abusive, offensive, or create a hostile professional or workplace environment. Sexual harassment may include sexual solicitation, physical advance, or verbal or non-verbal conduct that is sexual in nature. Racial harassment may include unnecessary, exaggerated, or unwarranted attention or attack, whether verbal or non-verbal, because of a person's race or ethnicity.

8. Employment Decisions

Sociologists have an obligation to adhere to the highest ethical standards when participating in employment related decisions, when seeking employment, or when planning to resign from a position.

8.01 Fair Employment Practices:

(a) When participating in employment-related decisions, sociologists make every effort to ensure equal opportunity and fair treatment to all full- and part-time employees. They do not discriminate in hiring, promotion, salary, treatment, or any other conditions of employment or career development on the basis of age; gender; race; ethnicity; national origin; religion; sexual orientation; disability; health conditions; marital, domestic, or parental status; or any other applicable basis proscribed by law.

(b) When participating in employment-related decisions, sociologists specify the requirements for hiring, promotion, tenure, and termination and communicate these requirements thoroughly to full- and part-time employees and prospective employees.

(c) When participating in employment-related decisions, sociologists have the responsibility to be informed of fair employment codes, to communicate this information to employees, and to help create an atmosphere upholding fair employment practices for full- and part-time employees.

(d) When participating in employment-related decisions, sociologists inform prospective full- and part-time employees of any constraints on research and publication and negotiate clear understandings about any conditions that may limit research and scholarly activity.

8.02 Responsibilities of Employees:

(a) When seeking employment, sociologists provide prospective employers with accurate and complete information on their professional qualifications and experiences.

(b) When leaving a position, permanently or temporarily, sociologists provide their employers with adequate notice and take reasonable steps to reduce negative effects of leaving.

9. Conflicts of Interest

Sociologists maintain the highest degree of integrity in their professional work and avoid conflicts of interest and the appearance of conflict. Conflicts of interest arise when sociologists' personal or financial interests prevent them from performing their professional work in an unbiased manner. In research, teaching, practice, and service, sociologists are alert to situations that might cause a conflict of interest and take appropriate action to prevent conflict or disclose it to appropriate parties.

9.01 Adherence to Professional Standards

Irrespective of their personal or financial interests or those of their employers or clients, sociologists adhere to professional and scientific standards in (1) the collection, analysis, or interpretation of data; (2) the reporting of research; (3) the teaching, professional presentation, or public dissemination of sociological knowledge; and (4) the identification or implementation of appropriate contractual, consulting, or service activities.

9.02 Disclosure

Sociologists disclose relevant sources of financial support and relevant personal or professional relationships that may have the appearance of or potential for a conflict of interest to an employer or client, to the sponsors of their professional work, or in public speeches and writing.

9.03 Avoidance of Personal Gain

(a) Under all circumstances, sociologists do not use or otherwise seek to gain from information or material received in a confidential context (e.g., knowledge obtained from reviewing a manuscript or serving on a proposal review panel), unless they have authorization to do so or until that information is otherwise made publicly available.

(b) Under all circumstances, sociologists do not seek to gain from information or material in an employment or client relationship without permission of the employer or client.

9.04 Decisionmaking in the Workplace

In their workplace, sociologists take appropriate steps to avoid conflicts of interest or the appearance of conflicts, and carefully scrutinize potentially biasing affiliations or relationships. In research, teaching, practice, or service, such potentially biasing affiliations or relationships include, but are not limited to, situations involving family, business, or close personal friendships or those with whom sociologists have had strong conflict or disagreement.

9.05 Decisionmaking Outside of the Workplace

In professional activities outside of their workplace, sociologists in all circumstances abstain from engaging in deliberations and decisions that allocate or withhold benefits or rewards from individuals or institutions if they have biasing affiliations or relationships. These biasing affiliations or relationships are: 1) current employment or being considered for employment at an organization or institution that could be construed as benefiting from the decision; 2) current officer or board member of an organization or institution that could be construed as benefiting from the decision; 3) current employment or being considered for employment at the same organization or institution where an individual could benefit from the decision; 4) a spouse, domestic partner, or known relative who as an individual could benefit from the decision; or 5) a current business or professional partner, research collaborator, employee, supervisee, or student who as an individual could benefit from the decision.

10. Public Communication

Sociologists adhere to the highest professional standards in public communications about their professional services, credentials and expertise, work products, or publications, whether these communications are from themselves or from others.

10.01 Public Communications

(a) Sociologists take steps to ensure the accuracy of all public communications. Such public communications include, but are not limited to, directory listings; personal resumes or curriculum vitae; advertising; brochures or printed matter; interviews or comments to the media; statements in legal proceedings; lectures and public oral presentations; or other published materials.

(b) Sociologists do not make public statements that are false, deceptive, misleading, or fraudulent, either because of what they state, convey, or suggest or because of what they omit, concerning their research, practice, or other work activities or those of persons or organizations with which they are affiliated. Such activities include, but are not limited to, false or deceptive statements concerning sociologists' (1) training, experience, or competence; (2) academic degrees; (3) credentials; (4) institutional or association affiliations; (5) services; (6) fees; or (7) publications or research findings. Sociologists do not make false or deceptive statements concerning the scientific basis for, results of, or degree of success from their professional services.

(c) When sociologists provide professional advice or comment by means of public lectures, demonstrations, radio or television programs, prerecorded tapes, printed articles, mailed material, or other media, they take reasonable precautions to ensure that (1) the statements are based on appropriate research, literature, and practice; and (2) the statements are otherwise consistent with this Code of Ethics.

10.02 Statements by Others

(a) Sociologists who engage or employ others to create or place public statements that promote their work products, professional services, or other activities retain responsibility for such statements.

(b) Sociologists make reasonable efforts to prevent others whom they do not directly engage, employ, or supervise (such as employers, publishers, sponsors, organizational clients, members of the media) from making deceptive statements concerning their professional research, teaching, or practice activities.

(c) In working with the press, radio, television, or other communications media or in advertising in the media, sociologists are cognizant of potential conflicts of interest or appearances of such conflicts (e.g., they do not provide compensation to employees of the media), and they adhere to the highest standards of professional honesty (e.g., they acknowledge paid advertising).

11. Confidentiality

Sociologists have an obligation to ensure that confidential information is protected. They do so to ensure the integrity of research and the open communication with research participants and to protect sensitive information obtained in research, teaching, practice, and service. When gathering confidential information, sociologists should take into account the long-term uses of the information, including its potential placement in public archives or the examination of the information by other researchers or practitioners.

11.01 Maintaining Confidentiality

(a) Sociologists take reasonable precautions to protect the confidentiality rights of research participants, students, employees, clients, or others.

(b) Confidential information provided by research participants, students, employees, clients, or others is treated as such by sociologists even if there is no legal protection or privilege to do so. Sociologists have an obligation to protect confidential information, and not allow information gained in confidence from being used in ways that would unfairly compromise research participants, students, employees, clients, or others.

(c) Information provided under an understanding of confidentiality is treated as such even after the death of those providing that information.

(d) Sociologists maintain the integrity of confidential deliberations, activities, or roles, including, where applicable, that of professional committees, review panels, or advisory groups (e.g., the ASA Committee on Professional Ethics).

(e) Sociologists, to the extent possible, protect the confidentiality of student records, performance data, and personal information, whether verbal or written, given in the context of academic consultation, supervision, or advising.

(f) The obligation to maintain confidentiality extends to members of research or training teams and collaborating organizations who have access to the information. To ensure that access to confidential information is restricted, it is the responsibility of researchers, administrators, and principal investigators to instruct staff to take the steps necessary to protect confidentiality.

(g) When using private information about individuals collected by other persons or institutions, sociologists protect the confidentiality of individually identifiable information. Information is private when an individual can reasonably expect that the information will not be made public with personal identifiers (e.g., medical or employment records).

11.02 Limits of Confidentiality

(a) Sociologists inform themselves fully about all laws and rules which may limit or alter guarantees of confidentiality. They determine their ability to guarantee absolute confidentiality and, as appropriate, inform research participants, students, employees, clients, or others of any limitations to this guarantee at the outset consistent with ethical standards set forth in 11.02(b).

(b) Sociologists may confront unanticipated circumstances where they become aware of information that is clearly health- or life-threatening to research participants, students, employees, clients, or others. In these cases, sociologists balance the importance of guarantees of confidentiality with other principles in this Code of Ethics, standards of conduct, and applicable law.

(c) Confidentiality is not required with respect to observations in public places, activities conducted in public, or other settings where no rules of privacy are provided by law or custom. Similarly, confidentiality is not required in the case of information available from public records.

11.03 Discussing Confidentiality and Its Limits

(a) When sociologists establish a scientific or professional relationship with persons, they discuss (1) the relevant limitations on confidentiality, and (2) the foreseeable uses of the information generated through their professional work.

(b) Unless it is not feasible or is counter-productive, the discussion of confidentiality occurs at the outset of the relationship and thereafter as new circumstances may warrant.

11.04 Anticipation of Possible Uses of Information

(a) When research requires maintaining personal identifiers in data bases or systems of records, sociologists delete such identifiers before the information is made publicly available.

(b) When confidential information concerning research participants, clients, or other recipients of service is entered into databases or systems of records available to persons without the prior consent of the relevant parties, sociologists protect anonymity by not including personal identifiers or by employing other techniques that mask or control disclosure of individual identities.

(c) When deletion of personal identifiers is not feasible, sociologists take reasonable steps to determine that appropriate consent of personally-identifiable individuals has been obtained before they transfer such data to others or review such data collected by others.

11.05 Electronic Transmission of Confidential Information

Sociologists use extreme care in delivering or transferring any confidential data, information, or communication over public computer networks. Sociologists are attentive to the problems of maintaining confidentiality and control over sensitive material and data when use of technological innovations, such as public computer networks, may open their professional and scientific communication to unauthorized persons.

11.06 Anonymity of Sources

(a) Sociologists do not disclose in their writings, lectures, or other public media confidential, personally identifiable information concerning their research participants, students, individual or organizational clients, or other recipients of their service which is obtained during the course of their work, unless consent from individuals or their legal representatives has been obtained.

(b) When confidential information is used in scientific and professional presentations, sociologists disguise the identity of research participants, students, individual or organizational clients, or other recipients of their service.

11.07 Minimizing Intrusions on Privacy

(a) To minimize intrusions on privacy, sociologists include in written and oral reports, consultations, and public communications only information germane to the purpose for which the communication is made.

(b) Sociologists discuss confidential information or evaluative data concerning research participants, students, supervisees, employees, and individual or organizational clients only for appropriate scientific or professional purposes and only with persons clearly concerned with such matters.

11.08 Preservation of Confidential Information

(a) Sociologists take reasonable steps to ensure that records, data, or information are preserved in a confidential manner consistent with the requirements of this Code of Ethics, recognizing that ownership of records, data, or information may also be governed by law or institutional principles.

(b) Sociologists plan so that confidentiality of records, data, or information is protected in the event of the sociologist's death, incapacity, or withdrawal from the position or practice.

(c) When sociologists transfer confidential records, data, or information to other persons or organizations, they obtain assurances that the recipients of the records, data, or information will employ measures to protect confidentiality at least equal to those originally pledged.

12. Informed Consent

Informed consent is a basic ethical tenet of scientific research on human populations. Sociologists do not involve a human being as a subject in research without the informed consent of the subject or the subject's legally authorized representative, except as otherwise specified in this Code. Sociologists recognize the possibility of undue influence or subtle pressures on subjects that may derive from researchers' expertise or authority, and they take this into account in designing informed consent procedures.

12.01 Scope of Informed Consent

(a) Sociologists conducting research obtain consent from research participants or their legally authorized representatives (1) when data are collected from research participants through any form of communication, interaction, or intervention; or (2) when behavior of research participants occurs in a private context where an individual can reasonably expect that no observation or reporting is taking place.

(b) Despite the paramount importance of consent, sociologists may seek waivers of this standard when (1) the research involves no more than minimal risk for research participants, and (2) the research could not practicably be carried out were informed consent to be required. Sociologists recognize that waivers of consent require approval from institutional review boards or, in the absence of such boards, from another authoritative body with expertise on the ethics of research. Under such circumstances, the confidentiality of any personally identifiable information must be maintained unless otherwise set forth in 11.02(b).

(c) Sociologists may conduct research in public places or use publicly available information about individuals (e.g., naturalistic observations in public places, analysis of public records, or archival research) without obtaining consent. If, under such circumstances, sociologists have any doubt whatsoever about the need for informed consent, they consult with institutional review boards or, in the absence of such boards, with another authoritative body with expertise on the ethics of research before proceeding with such research.

(d) In undertaking research with vulnerable populations (e.g., youth, recent immigrant populations, the mentally ill), sociologists take special care to ensure that the voluntary nature of the research is understood and that consent is not coerced. In all other respects, sociologists adhere to the principles set forth in 12.01(a)-(c).

(e) Sociologists are familiar with and conform to applicable state and federal regulations and, where applicable, institutional review board requirements for obtaining informed consent for research.

12.02 Informed Consent Process

(a) When informed consent is required, sociologists enter into an agreement with research participants or their legal representatives that clarifies the nature of the research and the responsibilities of the investigator prior to conducting the research.

(b) When informed consent is required, sociologists use language that is understandable to and respectful of research participants or their legal representatives.

(c) When informed consent is required, sociologists provide research participants or their legal representatives with the opportunity to ask questions about any aspect of the research, at any time during or after their participation in the research.

(d) When informed consent is required, sociologists inform research participants or their legal representatives of the nature of the research; they indicate to participants that their participation or continued participation is voluntary; they inform participants of significant factors that may be expected to influence their willingness to participate (e.g., possible risks and benefits of their participation); and they explain other aspects of the research and respond to questions from prospective participants. Also, if relevant, sociologists explain that refusal to participate or withdrawal from participation in the research involves no penalty, and they explain any foreseeable consequences of declining or withdrawing. Sociologists explicitly discuss confidentiality and, if applicable, the extent to which confidentiality may be limited as set forth in 11.02(b).

(e) When informed consent is required, sociologists keep records regarding said consent. They recognize that consent is a process that involves oral and/or written consent.

(f) Sociologists honor all commitments they have made to research participants as part of the informed consent process except where unanticipated circumstances demand otherwise as set forth in 11.02(b).

12.03 Informed Consent of Students and Subordinates

When undertaking research at their own institutions or organizations with research participants who are students or subordinates, sociologists take special care to protect the prospective subjects from adverse consequences of declining or withdrawing from participation.

12.04 Informed Consent with Children

(a) In undertaking research with children, sociologists obtain the consent of children to participate, to the extent that they are capable of providing such consent, except under circumstances where consent may not be required as set forth in 12.01(b).

(b) In undertaking research with children, sociologists obtain the consent of a parent or a legally authorized guardian. Sociologists may seek waivers of parental or guardian consent when (1) the research involves no more than minimal risk for the research participants, and (2) the research could not practicably be carried out were consent to be required, or (3) the consent of a parent or guardian is not a reasonable requirement to protect the child (e.g., neglected or abused children).

(c) Sociologists recognize that waivers of consent from a child and a parent or guardian require approval from institutional review boards or, in the absence of such boards, from another authoritative body with expertise on the ethics of research. Under such circumstances, the confidentiality of any personally identifiable information must be maintained unless otherwise set forth in 11.02(b).

12.05 Use of Deception in Research

(a) Sociologists do not use deceptive techniques (1) unless they have determined that their use will not be harmful to research participants; is justified by the study's prospective scientific, educational, or applied value; and that equally effective alternative procedures that do not use deception are not feasible, and (2) unless they have obtained the approval of institutional review boards or, in the absence of such boards, with another authoritative body with expertise on the ethics of research.

(b) Sociologists never deceive research participants about significant aspects of the research that would affect their willingness to participate, such as physical risks, discomfort, or unpleasant emotional experiences.

(c) When deception is an integral feature of the design and conduct of research, sociologists attempt to correct any misconception that research participants may have no later than at the conclusion of the research.

(d) On rare occasions, sociologists may need to conceal their identity in order to undertake research that could not practicably be carried out were they to be known as researchers. Under such circumstances, sociologists undertake the research if it involves no more than minimal risk for the research participants and if they have obtained approval to proceed in this manner from an institutional review board or, in the absence of such boards, from another authoritative body with expertise on the ethics of research. Under such circumstances, confidentiality must be maintained unless otherwise set forth in 11.02(b).

12.06 Use of Recording Technology

Sociologists obtain informed consent from research participants, students, employees, clients, or others prior to videotaping, filming, or recording them in any form, unless these activities involve simply naturalistic observations in public places and it is not anticipated that the recording will be used in a manner that could cause personal identification or harm.

13. Research Planning, Implementation, and Dissemination

Sociologists have an obligation to promote the integrity of research and to ensure that they comply with the ethical tenets of science in the planning, implementation, and dissemination of research. They do so in order to advance knowledge, to minimize the possibility that results will be misleading, and to protect the rights of research participants.

13.01 Planning and Implementation

(a) In planning and implementing research, sociologists minimize the possibility that results will be misleading.

(b) Sociologists take steps to implement protections for the rights and welfare of research participants and other persons affected by the research.

(c) In their research, sociologists do not encourage activities or themselves behave in ways that are health- or life-threatening to research participants or others.

(d) In planning and implementing research, sociologists consult those with expertise concerning any special population under investigation or likely to be affected.

(e) In planning and implementing research, sociologists consider its ethical acceptability as set forth in the Code of Ethics. If the best ethical practice is unclear, sociologists consult with institutional review boards or, in the absence of such review processes, with another authoritative body with expertise on the ethics of research.

(f) Sociologists are responsible for the ethical conduct of research conducted by them or by others under their supervision or authority.

13.02 Unanticipated Research Opportunities

If during the course of teaching, practice, service, or non-professional activities, sociologists determine that they wish to undertake research that was not previously anticipated, they make known their intentions and take steps to ensure that the research can be undertaken consonant with ethical principles, especially those relating to confidentiality and informed consent. Under such circumstances, sociologists seek the approval of institutional review boards or, in the absence of such review processes, another authoritative body with expertise on the ethics of research.

13.03 Offering Inducements for Research Participants

Sociologists do not offer excessive or inappropriate financial or other inducements to obtain the participation of research participants, particularly when it might coerce participation. Sociologists may provide incentives to the extent that resources are available and appropriate.

13.04 Reporting on Research

(a) Sociologists disseminate their research findings except where unanticipated circumstances (e.g., the health of the researcher) or proprietary agreements with employers, contractors, or clients preclude such dissemination.

(b) Sociologists do not fabricate data or falsify results in their publications or presentations.

(c) In presenting their work, sociologists report their findings fully and do not omit relevant data. They report results whether they support or contradict the expected outcomes.

(d) Sociologists take particular care to state all relevant qualifications on the findings and interpretation of their research. Sociologists also disclose underlying assumptions, theories, methods, measures, and research designs that might bear upon findings and interpretations of their work.

(e) Consistent with the spirit of full disclosure of methods and analyses, once findings are publicly disseminated, sociologists permit their open assessment and verification by other responsible researchers with appropriate safeguards, where applicable, to protect the anonymity of research participants.

(f) If sociologists discover significant errors in their publication or presentation of data, they take reasonable steps to correct such errors in a correction, a retraction, published errata, or other public fora as appropriate.

(g) Sociologists report sources of financial support in their written papers and note any special relations to any sponsor. In special circumstances, sociologists may withhold the names of specific sponsors if they provide an adequate and full description of the nature and interest of the sponsor.

(h) Sociologists take special care to report accurately the results of others' scholarship by using correct information and citations when presenting the work of others in publications, teaching, practice, and service settings.

13.05 Data Sharing

(a) Sociologists share data and pertinent documentation as a regular practice. Sociologists make their data available after completion of the project or its major publications, except where proprietary agreements with employers, contractors, or clients preclude such accessibility or when it is impossible to share data and protect the confidentiality of the data or the anonymity of research participants (e.g., raw field notes or detailed information from ethnographic interviews).

(b) Sociologists anticipate data sharing as an integral part of a research plan whenever data sharing is feasible.

(c) Sociologists share data in a form that is consonant with research participants' interests and protect the confidentiality of the information they have been given. They maintain the confidentiality of data, whether legally required or not; remove personal identifiers before data are shared; and if necessary use other disclosure avoidance techniques.

(d) Sociologists who do not otherwise place data in public archives keep data available and retain documentation relating to the research for a reasonable period of time after publication or dissemination of results.

(e) Sociologists may ask persons who request their data for further analysis to bear the associated incremental costs, if necessary.

(f) Sociologists who use data from others for further analyses explicitly acknowledge the contribution of the initial researchers.

14. Plagiarism

(a) In publications, presentations, teaching, practice, and service, sociologists explicitly identify, credit, and reference the author when they take data or material verbatim from another person's written work, whether it is published, unpublished, or electronically available.

(b) In their publications, presentations, teaching, practice, and service, sociologists provide acknowledgment of and reference to the use of others' work, even if the work is not quoted verbatim or paraphrased, and they do not present others' work as their own whether it is published, unpublished, or electronically available.

15. Authorship Credit

(a) Sociologists take responsibility and credit, including authorship credit, only for work they have actually performed or to which they have contributed.

(b) Sociologists ensure that principal authorship and other publication credits are based on the relative scientific or professional contributions of the individuals involved, regardless of their status. In claiming or determining the ordering of authorship, sociologists seek to reflect accurately the contributions of main participants in the research and writing process.

(c) A student is usually listed as principal author on any multiple authored publication that substantially derives from the student's dissertation or thesis.

16. Publication Process

Sociologists adhere to the highest ethical standards when participating in publication and review processes when they are authors or editors.

16.01 Submission of Manuscripts for Publication

(a) In cases of multiple authorship, sociologists confer with all other authors prior to submitting work for publication and establish mutually acceptable agreements regarding submission.

(b) In submitting a manuscript to a professional journal, book series, or edited book, sociologists grant that publication first claim to publication except where explicit policies allow multiple submissions. Sociologists do not submit a manuscript to a second publication until after an official decision has been received from the first publication or until the manuscript is withdrawn. Sociologists submitting a manuscript for publication in a journal, book series, or edited book can withdraw a manuscript from consideration up until an official acceptance is made.

(c) Sociologists may submit a book manuscript to multiple publishers. However, once sociologists have signed a contract, they cannot withdraw a manuscript from publication unless there is reasonable cause to do so.

16.02 Duplicate Publication of Data

When sociologists publish data or findings that they have previously published elsewhere, they accompany these publications by proper acknowledgment.

16.03 Responsibilities of Editors

(a) When serving as editors of journals or book series, sociologists are fair in the application of standards and operate without personal or ideological favoritism or malice. As editors, sociologists are cognizant of any potential conflicts of interest.

(b) When serving as editors of journals or book series, sociologists ensure the confidential nature of the review process and supervise editorial office staff, including students, in accordance with practices that maintain confidentiality.

(c) When serving as editors of journals or book series, sociologists are bound to publish all manuscripts accepted for publication unless major errors or ethical violations are discovered after acceptance (e.g., plagiarism or scientific misconduct).
(d) When serving as editors of journals or book series, sociologists ensure the anonymity of reviewers unless they otherwise receive permission from reviewers to reveal their identity. Editors ensure that their staff conform to this practice.
(e) When serving as journal editors, sociologists ensure the anonymity of authors unless and until a manuscript is accepted for publication or unless the established practices of the journal are known to be otherwise.
(f) When serving as journal editors, sociologists take steps to provide for the timely review of all manuscripts and respond promptly to inquiries about the status of the review.

17. Responsibilities of Reviewers

(a) In reviewing material submitted for publication, grant support, or other evaluation purposes, sociologists respect the confidentiality of the process and the proprietary rights in such information of those who submitted it.
(b) Sociologists disclose conflicts of interest or decline requests for reviews of the work of others where conflicts of interest are involved.
(c) Sociologists decline requests for reviews of the work of others when they believe that the review process may be biased or when they have questions about the integrity of the process.
(d) If asked to review a manuscript, book, or proposal they have previously reviewed, sociologists make it known to the person making the request (e.g., editor, program officer) unless it is clear that they are being asked to provide a reappraisal.

18. Education, Teaching, and Training

As teachers, supervisors, and trainers, sociologists follow the highest ethical standards in order to ensure the quality of sociological education and the integrity of the teacher-student relationship.

18.01 Administration of Education Programs

(a) Sociologists who are responsible for education and training programs seek to ensure that the programs are competently designed, provide the proper experiences, and meet all goals for which claims are made by the program.
(b) Sociologists responsible for education and training programs seek to ensure that there is an accurate description of the program content, training goals and objectives, and requirements that must be met for satisfactory completion of the program.
(c) Sociologists responsible for education and training programs take steps to ensure that graduate assistants and temporary instructors have the substantive knowledge required to teach courses and the teaching skills needed to facilitate student learning.
(d) Sociologists responsible for education and training programs have an obligation to ensure that ethics are taught to their graduate students as part of their professional preparation.

18.02 Teaching and Training

(a) Sociologists conscientiously perform their teaching responsibilities. They have appropriate skills and knowledge or are receiving appropriate training.
(b) Sociologists provide accurate information at the outset about their courses, particularly regarding the subject matter to be covered, bases for evaluation, and the nature of course experiences.
(c) Sociologists make decisions concerning textbooks, course content, course requirements, and grading solely on the basis of educational criteria without regard for financial or other incentives.

(d) Sociologists provide proper training and supervision to their teaching assistants and other teaching trainees and take reasonable steps to ensure that such persons perform these teaching responsibilities responsibly, competently, and ethically.

(e) Sociologists do not permit personal animosities or intellectual differences with colleagues to foreclose students' or supervisees' access to these colleagues or to interfere with student or supervisee learning, academic progress, or professional development.

19. Contractual and Consulting Services

(a) Sociologists undertake grants, contracts, or consultation only when they are knowledgeable about the substance, methods, and techniques they plan to use or have a plan for incorporating appropriate expertise.

(b) In undertaking grants, contracts, or consultation, sociologists base the results of their professional work on appropriate information and techniques.

(c) When financial support for a project has been accepted under a grant, contract, or consultation, sociologists make reasonable efforts to complete the proposed work on schedule.

(d) In undertaking grants, contracts, or consultation, sociologists accurately document and appropriately retain their professional and scientific work.

(e) In establishing a contractual arrangement for research, consultation, or other services, sociologists clarify, to the extent feasible at the outset, the nature of the relationship with the individual, organizational, or institutional client. This clarification includes, as appropriate, the nature of the services to be performed, the probable uses of the services provided, possibilities for the sociologist's future use of the work for scholarly or publication purposes, the timetable for delivery of those services, and compensation and billing arrangements.

20. Adherence to the Code of Ethics

Sociologists have an obligation to confront, address, and attempt to resolve ethical issues according to this Code of Ethics.

20.01 Familiarity with the Code of Ethics

Sociologists have an obligation to be familiar with this Code of Ethics, other applicable ethics codes, and their application to sociologists' work. Lack of awareness or misunderstanding of an ethical standard is not, in itself, a defense to a charge of unethical conduct.

20.02 Confronting Ethical Issues

(a) When sociologists are uncertain whether a particular situation or course of action would violate the Code of Ethics, they consult with other sociologists knowledgeable about ethical issues, with ASA's Committee on Professional Ethics, or with other organizational entities such as institutional review boards.

(b) When sociologists take actions or are confronted with choices where there is a conflict between ethical standards enunciated in the Code of Ethics and laws or legal requirements, they make known their commitment to the Code and take steps to resolve the conflict in a responsible manner by consulting with colleagues, professional organizations, or the ASA's Committee on Professional Ethics.

20.03 Fair Treatment of Parties in Ethical Disputes

(a) Sociologists do not discriminate against a person on the basis of his or her having made an ethical complaint.

(b) Sociologists do not discriminate against a person based on his or her having been the subject of an ethical complaint. This does not preclude taking action based upon the outcome of an ethical complaint.

20.04 Reporting Ethical Violations of Others

When sociologists have substantial reason to believe that there may have been an ethical violation by another sociologist, they attempt to resolve the issue by bringing it to the attention of that individual if an informal resolution appears appropriate or possible, or they seek advice about whether or how to proceed based on this belief, assuming that such activity does not violate any confidentiality rights. Such action might include referral to ASA's Committee on Professional Ethics.

20.05 Cooperating with Ethics Committees

Sociologists cooperate in ethics investigations, proceedings, and resulting requirements of the American Sociological Association. In doing so, they make reasonable efforts to resolve any issues of confidentiality. Failure to cooperate may be an ethics violation.

20.06 Improper Complaints

Sociologists do not file or encourage the filing of ethics complaints that are frivolous and are intended to harm the alleged violator rather than to protect the integrity of the discipline and the public.

Note: This revised edition of the ASA Code of Ethics builds on the 1989 edition of the Code and the 1992 version of the American Psychological Association's Ethical Principles of Psychologists and Code of Conduct.

Guidelines for Research in
Partnership with Developing Countries
11 Principles

Swiss Commission for Research Partnership with Developing Countries
KFPE
Berne, 1998

(ABSTRACTS)

Introduction to the Guidelines

Basic principles

Research in and with developing countries should – indeed, must – lead to the strengthening of their research capacity [1]. This requires mutual respect, honesty and openness. The partners must be able to communicate effectively, and must be prepared to commit themselves to a long-term involvement. In addition, research relevant to development should have results that are visible and palpable for the local community [2]. The considerable experience of local people should be taken seriously and made use of whenever possible.

A basic requirement for the establishment of mutual trust is a continuing dialogue and the exchange of experience among all those involved, including the members of the local community. This includes the people who do not have an «official voice», especially the women. In spite of the rigours of scientific work there is a need for personal – even emotional – involvement, and an inner readiness to take part in what is going on. This is particularly important for partners from industrialised countries. Not only do they need to be modest, but they may well find that the project makes greater demands on their time, endurance and perseverance than their work has done in the past[3,4]

Tackling common problems together can motivate all the partners to cooperate actively. The best possible division of tasks and responsibilities, based on the different strengths of the partners, offers the best chance that synergic effects will be produced and made use of, and that all those involved – right up to the end-user – will really benefit from the research activities.

Like any kind of cooperative enterprise, research partnership must always be orientated towards particular goals and a specific setting. Research partnership is therefore not always easy to categorise, but nevertheless, three levels can be distinguished in connection with the type, scope and duration of the collaboration: ***Cooperative Projects*** [5], ***Cooperative Programmes***[6], and

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[1] see e.g. RAWOO (Advisory Council for Scientific Research in Development Problems (The Netherlands) 1996: Towards a European Science & Technology Policy for Development. Publications no. 13: 17

[2] RAWOO 1994: Development and strengthening of research capacity in developing countries. Publications no. 5
RAWOO-Home-Page: http://www.nufficcs.nl/ciran/rawoo

[3] De Lattre 1996: Propositions pour une réorientation de la recherche franÁaise au service du développement. Rapport final. Comité National de coordination pour la recherche au service du développement. 46 pages

[4] Kaufmann Chr., 1997: Vanuatu. Kunst der Südsee. Museum der Kulturen Basel (Hg.), Christoph Merian Verlag Basel

[5] Projects: Generally directed towards tackling a discrete, concrete problem, of relatively short duration (a few years) and usually with a relatively modest level of personnel and financial support.

Institutional Cooperation[7]. The Guidelines apply first and foremost to cooperative projects, which involve the most people. Once a problem has been identified, research in partnership essentially develops in four stages.

1. One or more partners are found who share an interest in doing research on some aspect of the problem.
2. The partners work together to clarify the theme, and make concrete plans for carrying out the work, including details of organisation and financing.
3. The partners work together on the research, sharing the responsibility for leadership and preparing reports and publications together.
4. Finally, the collaborative effort must be brought to a conclusion. The partners may go their separate ways, or they may continue to work together on new tasks, for example putting the results into practice, doing further research along the same lines, or tackling new problems together.

About the contents

The Guidelines comprise **11 Principles** for research in partnership between an industrialised country (in this case, Switzerland) and developing countries. For each, there is a description of the ***overall aim***, ***practical suggestions*** as to how it can be achieved, and a ***«checklist»*** of questions for evaluating how far a specific proposal fulfils the aim. The ***overall aim*** represents in one sense an ideal long-term goal - the maximum possible level of partnership that the project could reach. How far the goal can be reached will depend on the situation. The ***practical suggestions*** for implementation offer possibilities for achieving the aim. Finally, the ***evaluation questions*** are intended as a working tool - a «checklist» – for both applicants and funding agencies. They will naturally need to be adjusted to the particular situation and if necessary amplified; in the present form they make no claim to completeness.

The 11 Principles are all closely linked, and no hard-and-fast boundaries can be drawn between them. The first seven are more immediately concerned with the details of how to set up and implement a research project in partnership, whereas Principles 8 to 11 go beyond what is usually considered as «research» in a strict sense. **Principle 10, «Increase research capacity» is of central importance. It is the goal that should be reached if the previous nine principles are followed.** It is precisely those aspects of research in partnership that go beyond the usual definition of research that represent the «Change of Course» postulated in the Foreword. In another publication[8] from a group of Swiss scientists we read, *«Researchers need to accept their share of responsibility in social development by considering the specific needs of politics, economy and society»*. This statement does not only apply to industrialised countries but also – to an even greater extent – to the countries now in the process of development. Research workers can no longer feel that their job is done when the results of their work have been published. They should also concern themselves as far as they are able with putting the results into practice. In a

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[6] Programmes: Generally deal with a complex of problems; usually medium-term (some years) and often more extensive than a project; a programme may incorporate a number of separate projects. In the long term, programmes require more personnel and financial support.

[7] Institutional cooperation: Mutually beneficial cooperation between institutions in one or more areas . They are generally based on an agreement which is intended to last for a long time - often for an indefinite period. The cooperation is not necessarily more extensive than collaboration within a programme. The situation in which the institutes must work (political, administrative etc.) may play a more important role.

[8] Visions by Swiss Researchers. Research on Sustainability and Global Change – Visions in Science Policy by Swiss Researchers. Obtainable from ProClim-, Bärenplatz 2, CH-3011 (32 pages) (or available on http://www.proclim.unibe.ch/visions.html)

comprehensive sense, they should take into account the far-reaching effects of their activity on human life and human experience.

Experience has taught that for those who want to embark on a partnership, one of the greatest difficulties is **to find new, suitable partners**. This is true for scientists both in industrialised and in developing countries - but is probably even more difficult for the latter. The mechanisms that scientists have for making contact with each other function far less effectively for scientists in developing countries, because their access to scientific journals, international conferences and the like is limited. The problem has been recognised, but is still waiting for a really satisfactory solution - though the further spread of modern means of communication, especially e-mail and the Internet, may help to some extent.

The Guidelines go into the question of the **management** of the available **financial resources** in Principle 5. However, no information is given about the acquisition of funds; the possibilities are very varied, change frequently, and are different in every situation. Information can be obtained from various sources. The basic principle needs to be stressed that each partner should make a contribution, though this does not necessarily have to be financial. If all parties contribute, it becomes more likely that the research priorities and needs of all parties will be adequately taken into consideration[9] This increases the chances that the cooperation will be successful, following the principle of reciprocity in rights and duties.

A further question that is not considered in the Guidelines is that of the criteria by which the relevance and scientific quality of a project might be judged. It can be assumed that these are generally well known, and as a rule the donors of funds will insist upon their being followed. However, it should be emphasised that the criteria used to evaluate research activities in partnership should consider both their ***scientific merit*** and the extent to which they will lead to ***genuine partnership***.

The 11 Principles of Research Partnership

1st Principle:

Decide on the objectives together

Overall aim

Often it is the partner from the North who takes the initiative and makes suggestions about topics for research. However, it is not really helpful to offer possible partners a more-or-less completely formulated and developed research project. They will then hardly be in a position to incorporate their own ideas and needs. Instead, the theme should be decided upon and the project developed in discussion between all the partners, including the people who will eventually use the results, who should be actively involved in the work as far as this is possible, and to the extent that is feasible for them.

Two aspects must be considered. On the one hand, research priorities must be set which fit in with the interests of all those involved. On the other hand, these general priorities must be distinguished from the research question to be answered by a particular project. This needs to be

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[9] RAWOO 1996 (see footnote 14)

precisely formulated. It will be based on one or more working hypotheses. As far as possible, the actual methods used for tackling the research should be participatory ones[10]. These may have to be newly developed, and will need to be adapted as the research proceeds.

Since the problems to be tackled are usually so complex, a form of collaboration will be needed that promotes trans-disciplinarity and holistic thinking[11]. Such collaboration is most likely to find appropriate answers to socially significant problems.

Practical suggestions

Someone who has an idea for a research project and would like to carry it out in collaboration with a partner should go to the partner as soon as possible and discuss and plan the project in detail. This will avoid essentially one-sided interests being considered. If a project is one-sided, the partner whose interests are neglected may not really be able to identify with it. It must be remembered that the process in which the partners «find» each other is usually very time-consuming. This is particularly true for the members of the teams who are directly involved in the research activities. Nevertheless, the effort is rewarding in many different ways.

In order to involve wider circles – including the local population – in both the preparations and the actual research work, special meetings need to be organised, and if necessary information must be prepared in a form in which it can be understood by the general public[12]. Collaboration with NGOs can be very helpful for this purpose. Wherever possible, local traditional knowledge should be taken into account. This can help to avoid false assessments of the situation by outside «experts», and can prepare the ground at an early stage for putting the expected results into practice.

Checklist

_ Who originally proposed the project?
_ Is the research question precisely formulated? Do all the participants understand it?
_ Are the working hypotheses clearly formulated, and have the methods for addressing them been decided upon?
_ Did all the relevant actors and people who will be affected by the research participate in developing the theme of the research?
_ Does the project take the interests of all the participants into consideration, especially those of the final user in the South?
_ Does the research planned fit into the partners' existing national or regional research policies?
_ Does it serve the interests of all the partners?
_ Does the proposed research give due consideration to the social, cultural, political, economic, ecological and technical needs and situation of the partners?
_ If «yes», how?
_ Who are likely to be the main beneficiaries of the knowledge resulting from the planned research activities?
_ Researchers From Developing Countries / From Industrialised Countries
_ Research Institutions From Developing Countries / From Industrialised Countries
_ Government bodies From Developing Countries / From Industrialised Countries
_ Private industry From Developing Countries / From Industrialised Countries

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[10] Bolay J.-C. et al. (in preparation): Environnement urbain – Recherche et action dans les pays en développement

[11] See ProClim- (footnote 21)

[12] See Appendix

_ NGOs	From Developing Countries / From Industrialised Countries
_ The population	From Developing Countries / From Industrialised Countries

_ Others (which?)

_ Is the traditional knowledge of the partner/ the local population incorporated in the research plans?

_ If «yes», how?

2nd Principle:

Build up mutual trust

Overall aim

Without mutual trust, cooperative work can hardly be imagined. The creation of trust between partners who may be very different requires time and patience, and considerable ability to put oneself in another's place. Prejudices must be got rid of, and a framework must be created that will stimulate the desire for an honest and open research collaboration.

Besides cooperation with partners who are already well-known, it is desirable to look systematically for new contacts and relationships, not only to enlarge the personal networks of the participants, but to strengthen those of the collaborating institutions.

Practical suggestions

Positive experiences in the past promote trust; therefore it is often a good idea to take up contact again with research workers, research institutions, government bodies and communities with whom previous collaboration has been successful. It is a good idea to analyse the earlier collaboration carefully, and characterise all the partners as objectively as possible. It is also important to look at how they are embedded in their social, institutional, political and economic framework. This helps to avoid false assessments and exaggerated expectations, and makes it easier to take action quickly to avoid negative consequences. New partners must be found by a process of active searching, for example in lists of publications, in the Internet or at international conferences. If possible, personal contact should be made. Visiting a research institute that is being considered, or asking for references, can provide valuable information about a hitherto unknown partner. It is worth considering short-term exchange visits so that researchers can get to know each other in a working situation before beginning formal collaboration.

Checklist

_ Do all the partners know each other well enough, and do they trust each other (positive or negative experiences)?

_ Are descriptive outlines and references available for all suggested partners?

_ Are there plans to make a systematic search for other partners?

_ If «yes»: Who? How?

3rd Principle:

Share information; develop networks

Overall aim

A well-functioning communication system is decisive for satisfactory collaboration between partners who are often far apart geographically. It is vital to be able to exchange information regularly and comprehensively – to set up a functioning «network». But in addition, since there is often a considerable «cultural distance» between the partners, it is necessary for them to adjust their ways of thinking and expressing themselves so that they can come closer to each other. Without both of these, effective coordination is impossible. Ideally, all partners should have a comparable level of information and knowledge about the joint research activities and the environment in which they are being carried out. This means – especially for the partners in the South – being linked to regional and international information networks.

Practical suggestions

First and foremost, it must be made clear to all those involved – whether they are working at home or abroad, and including students – that communication within the group is extremely important.

The next step is to find out what means of communication are available to the partners. If these are not adequate, action must be taken to enable the partners to acquire the necessary infrastructure (telephones, telefax-machines, computers with e-mail or Internet connections). Such additional expenses should be included in the budget.

In addition, it is a help to have clear agreements about the regular exchange of information. Frequent and regular communication can help greatly to reduce the somewhat isolated position in which the Southern partners often find themselves.

Checklist

_ Has provision been made on both organisational and technical levels for all the partners to have sufficient regular contact with each other?

_ If «yes», what has been done? What technical means of communication are available?

_ If «no», will it be possible to support the partners in improving or expanding their technical facilities?

_ If so, how?

_ Do all the partners have adequate opportunities (and the necessary technical equipment) to make contact with international organisations, data banks etc? Is everybody sufficiently familiar with the use of the technical equipment that is available?

_ If not, is the project in a position to support the partners in carrying out necessary extensions and improvements to their technical infrastructure? How?

4th Principle:

Share responsibility

Overall aim
Both the scientific and the technical leadership and management responsibility for the project should be carried as far as possible by all the partners, taking into consideration the competence and the resources of each. If all the partners are included at all levels of the project, they will identify more strongly with the research activities. Experience has shown that a project is very often perceived as belonging exclusively to the Northern partners; in the long run, this makes it difficult for the Southern partners to identify with the activities. If all partners are involved in administration, it also gives those with less experience the opportunity to gain expertise in research management.

Practical suggestions
An early discussion between the partners to clarify the exact division of responsibility for the management of the project is of paramount importance, especially when the partners come from different cultural backgrounds. As the discussions often take place in a language which is foreign to all the participants, misunderstandings can very easily arise. It is to be recommended that the division of responsibilities should be defined in face-to-face discussion, and recorded in writing. In many countries, agreements made with the partners will have to be confirmed by their superiors.

Checklist

_ Will all the partners be included in the scientific supervision and the administrative responsibility?

_ Will all the responsible partners have an opportunity to see all the documents relevant to them?

_ Are the personal, organisational and financial conditions necessary for the taking over of responsibility fulfilled in the case of all partners?

_ If not, what needs to be done?

5th Principle:

Create transparency

Overall aim
If all the partners contribute to the resources needed for the planned project their commitment to the common enterprise will be strengthened. The worth of contributions made in forms other than money must be appropriately acknowledged. To satisfy the need for transparency, the source and amount of all resources, especially money, and the way they have been used, must be declared openly to all partners. Financial decisions should as far as possible be taken by all the partners together– and the amount of material support given should not be the basis for allowing some partners a stronger voice in decision-making than others.

Practical suggestions
To avoid conflict, it is advisable to prepare a binding agreement on paper (a «Memorandum of Understanding») which lays down the contribution to be made by all of the partners to the work, and their rights and duties. In order that the partners who are entitled to do so can assure

themselves that the agreement is being adhered to, they must be allowed unlimited access to the relevant documents. Regular balancing of the accounts, audits, and periodic checking of inventories are also measures which help to create transparency. Furthermore, the requirements of donors for financial statements must be fulfilled.

Checklist

- Are the mutually agreed financial and other contributions and the rights and duties of all partners recorded in writing?
- Will all partners be fully informed about where financial and other resources come from, how their use is planned, and what they have in fact been used for?
- Are there clear and fair rules about who has the authority to make what financial decisions?

6th Principle:

Monitor and evaluate the collaboration

Overall aim

Both the progress of the research, and the development and functioning of the partnership, should be continuously monitored[13]. Furthermore, there should be regular internal or external evaluations, which should assess as accurately as possible how successful (or unsuccessful) the project has been from the point of view of partnership in all its aspects: management, communication, decision-making, implementation, improvement of the capacities of all partners, etc.

Practical suggestions

Exchange of information and regular meetings help the partners to become aware of problems in good time, and to deal with them effectively. In many situations, it is a good idea to ask each of the partners to keep a diary. Interim reports etc. should whenever possible be written jointly. Drafts must be shown to all partners, and their comments invited. For periodic internal evaluations the criteria should be worked out together, and as early as possible; they should be adapted if necessary if the situation changes. For external evaluations care must be taken that the evaluating team includes representatives from developing as well as from industrialised countries. The evaluators must be free to carry out the evaluation as they see fit, in the framework of the task assigned to them.

Checklist

- Is monitoring of the functioning of the partnership foreseen?
    - If «yes», how is it to be carried out?
- In internal evaluation, are all the partners actively involved in a balanced way?
    - If not, why not?
- Have the criteria for internal evaluation been jointly defined, and are they known to all?
- Is an external evaluation advisable?
- If so, is the evaluating group appropriately constituted and is its task appropriately defined?
- Are the planned or promised financial resources adequate for monitoring and evaluation?

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[13] «Monitoring» requires the constant checking of achievements against a catalogue of defined indicators (criteria)

7th Principle:

Disseminate the results

Overall aim

It is a basic principle that there should be unlimited access to the results of research.

According to the situation, research projects in partnership between developing and industrialised countries may bring very different partners together. Not all of them will have the same experience in publishing their results, and certainly not the same access to appropriate media. Care must therefore be taken that all partners can take part to the proper extent in the dissemination of the results. This is especially true for scientific papers in respected international journals[14].

Since research projects in partnership between industrialised and developing countries are very often directed towards concrete problems, care should be taken that the results of the research are also communicated adequately to the people who will finally use them. This will smooth the way for putting the results into practice with the active participation of the local community.

Practical suggestions

Because of differences in experience with publishing, the partners involved will need to work closely together in preparing papers. All those who participated in the work should have the same rights, e.g. to be named as one of the first authors, but there is no justification for making concessions, for example including as authors people who made no significant contribution.

To make the results widely available, they will also need to be described in a way that can be understood by the general public, if necessary translated into local languages. The transfer of knowledge can take place in many ways, for example through lectures, travelling exhibitions, discussions, drama etc. Very often, the responses to efforts like this can be useful to the research team as well[15]. For scientists, the task of informing the public about the results is often an unaccustomed and difficult one; it may be advisable to request the help of more experienced people, institutions or organisations (e.g. a local NGO; see the case studies in the Appendix).

Checklist

_ Must access to or dissemination of the results of the research be limited?

_ If so, whose access should be limited? Why?

_ Are publications for a wider audience planned as well as scientific papers in international and national journals?

_ If so, what?

_ Are there concrete plans for passing on the new knowledge resulting from the project to the people who are directly affected?

_ If so, what is planned? (Possibilities include: seminars, workshops, conferences, lectures, public meetings, information through radio and television, travelling exhibitions, clearly-written leaflets etc. for the general public ...)

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[14] See activities of the International Federation of Science Editors (IFSE), Italy; http://www.cmns.mnegri.it/en/ifse/

[15] See the Convention of Lomé and RAWOO 1996 (footnote 14)

_ Are there plans to include appropriate people out of the target group («opinion leaders», «stakeholders», important local and regional actors) in the process of spreading the information and putting it into practice. Is including them a practical possibility?

_ If «yes»: Who? How?

8th Principle:

Apply the results

Overall aim

Research in partnership between developing and industrialised countries often claims that it is related to real life and is concerned, at least to some extent, with the problems of disadvantaged communities. Partnership projects thus raise expectations among the partners from the developing country and in the community. But these hopes are often disappointed – for example, very often the scientists fail to come back to the place where they carried out a field survey, even to say what they found – let alone to help with putting the results to use. It is not enough to disseminate the results, however good the format is. As far as it can, the research team has an obligation to ensure that the results are really used to benefit the target group.

Practical suggestions

The process of converting scientific results into a practical project and actually implementing it is extremely complex. All kinds of problems can arise in practice, for instance with the acceptance of the project, the actual methods to be used, the finances or the distribution of responsibility. It is almost essential to work together with people or institutions like NGOs and government bodies who already have a particularly good contact with the community, and in some cases also with commercial enterprises – it may even be best to establish a special firm for the purpose of making use of the research results. It is always a good idea to keep political decision-makers and/or government bodies well informed about the progress of the research and its results, and discuss with them possible ways of putting the results into practice, whether or not they are directly concerned. This can help to convince government officials of the importance of the research, so that once the actual research phase is over they will play an active part in ensuring that the results can be put into practice, and the expectations of the community fulfilled, without unnecessary delay.

Checklist

_ Are there concrete plans, considering the local, national and regional conditions, to use the results of the research for the benefit of the target group(s)?

_ If so, what kind?

_ If not, why not?

_ Will political decision-makers, government bodies and NGOs be informed periodically about the progress of the research, and will possible steps towards application be discussed with them?

_ If «yes»: Which? How?

_ Will all the people concerned take part in the plans to put the results into practice, including the members of the target group(s)?

If «yes»: Which? How?

9th Principle:

Share profits equitably

Overall aim
Research results have intellectual worth, and may also have a commercial value. All partners should share equally in the benefits of both. A very frequent complaint of partners from developing countries – and without a doubt one that is often justified – is that partners from industrialised countries have published results under their own names that were the results of collaborative work (and have then held the copyright), or have even benefited financially (taking out patents). This should not be allowed to happen.

Practical suggestions
When results are reported, all those who were involved to any significant extent should appear – as authors of papers and reports, speakers at meetings and in public lectures, in radio and television programmes etc. Due credit should also be given to other people who took part in the project, for instance informants who contributed traditional knowledge. It is to be recommended that the right to publish results should be discussed beforehand and laid down in writing. Any conditions laid down by the funding agency will also have to be taken into consideration.

The results of research on some topics may have a considerable potential commercial value. Again, the legal rights of all partners to the expected results should be discussed, and preferably recorded in writing, as far as possible before the research is done. International law (e.g. concerning patent rights) and the national regulations of the host country must be considered.

Checklist
_ Will all the partners be appropriately considered when the results of the research are published?
_ Who will make the decisions about joint publications?
_ Who will be shown drafts etc. before publication?
_ Have binding agreements been made about the rights of all partners in case the results prove to be of potential commercial value?
_ If so, what?
_ Who should be allowed to use the economically valuable results, and under what conditions?

10th Principle:

Increase research capacity

Overall aim
In addition to the hoped-for results of the research activities, the chief concern when research partnerships are formed is to strengthen the total capacity of all those involved for doing effective research, both on the individual and on the institutional level[16]. In this process, the different personal and institutional backgrounds and possibilities must be taken into account[17].

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[16] «Capacity building» means the improvement of the competence of an individual research worker or of a group in various areas (technical, scientific, management etc). «Institution building» is the creating of new institutions or the support of existing ones (Universtities, Institutes, Research Centres etc.) in all areas (

Something that is particularly to be promoted is research partnership between developing countries («South-South» collaboration). In such partnerships the partners may well share a similar background to their research activities, and suffer from similar problems. The need for South-South cooperation has been explicitly expressed by representatives of countries that are not yet industrialised and those that are in the process of industrialisation. As was said in the foreword, there is a strong commitment on the part of many scientists from the «South» to work together to raise their achievements in research to the level of those in industrialised countries[18]. The latter should do all they can to support them in their efforts, especially where the essential support of their own governments is missing.

Practical suggestions

For the participating research workers, a stay in another country as a guest or for further education and training can offer an opportunity to gather valuable experience, learn new methods, exchange information and make new contacts. Even the provision of names and addresses can be a valuable service, since the partners from industrialised countries often have more complete information.

Formal support for institutions, with agreements, contracts of cooperation, management advice etc., and also help with the extension of their infrastructure, can also contribute to increasing the attractiveness of «developing countries» as sites for doing research.

Checklist

_ Is it to be expected that the planned collaborative research activity will contribute to increasing the scientific capacity of all the partners?

_ If «yes», what are the benefits for the research workers involved and their institutions?

_ What importance has the research project for the development of that field in the country itself?

_ Are there plans for the exchange of partners for further training?

_ If so, who? When? For how long?

_ Which concrete support measures are foreseen with the aim of strengthening collaboration among developing countries?

_ Creating new contacts

_ Promoting the exchange of information

_ Organisation of meetings

_ Planning and carrying out common research projects

_ Financial support

_ Others (which?)

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political, administrative, financial, personal). – See also Wils, F., 1995: Building up and strengthening research capacity in Southern countries. RAWOO Publications no. 9 (48 pages).

[17] Bhagavan, M.R., 1992: The SAREC Model: Institutional cooperation and the strengthening of national research capacity in developing countries. Stockholm: SAREC.

[18] TWAS, see footnote 5

11th Principle:

Build on the achievements

Overall aim
The new knowledge and insights that have been obtained as a result of the joint efforts of all the partners must not be lost when the project comes to an end. If this happens, all the investment of energy, time and money will be wasted. If a project is successful there should be at least three valuable outcomes: new knowledge, a contribution to sustainable development, and new or more highly developed research capacities. This last is particularly important.

The new knowledge will be recorded in publications (Principles 7 and 9). Making a contribution to development means that the new knowledge must be applied in practice in a sustainable way (Principle 8). If newly-developed research capacity is to be maintained two things are needed. Existing institutions must continue to thrive, or new ones must be founded, and the people who worked in the project must be able to find suitable jobs under acceptable conditions.

Even in industrialised countries, institutions often have difficulty in offering their employees appropriate jobs when they return from a project in a developing country. The partners from developing countries are confronted with much more intractable problems from the point of view of employment, or even concerning the continued existence of their institutions, once the collaborative research is finished. It can then happen that for good scientists from developing countries, the temptation to leave and move to an industrialised country where the job prospects are more promising becomes too great («brain drain»). Others find themselves forced to take on unskilled work, or work not commensurate with their qualifications, in order to earn a living.

Practical suggestions
The key question is how far world-wide research is perceived as an important and urgent activity. The respect paid to research in developing countries needs to be increased – but this respect has to be earned, with recognisable achievements and good public information. Only then is there a hope that research institutions will be given more private and State support, and those who work in them will be better paid. In these efforts the institutions of the developing countries need support.

Above all, partners and their institutions must not simply be left to themselves after the joint project has been completed, but as far as possible there should be frequent personal contacts and a lively exchange of information (e.g. with joint seminars, lectures etc.). Overcoming intellectual isolation is an important contribution (and a moral obligation) that can help to prevent the emigration of the most competent scientists from developing countries. Contact with the international scientific community is of prime importance.

Measures aimed specifically at helping to ensure that the partners find further professional (scientific) employment must be considered. One such measure is to help them in obtaining mandates to do research in their own country on behalf of international organisations, NGOs etc.[19]. Efforts need to be made to give further help (financial, advisory etc.) to partner-institutions to help them to continue to function effectively – perhaps even to help them to expand.

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[19] In this context, the activities of the 'International Foundation for Science' (IFS, Stockholm) are particularly successful (see IFS-Home-Page: http://ifs.plants.ox.ac.uk/ifs/ifs.htm)

Checklist

_ Will the results obtained be used, in an appropriate form, to increase the general awareness of the importance of research in developing countries?

_ If «yes», how?

_ Are provisions being made, and support given, to ensure that partners from developing countries who have received training will be further employed in their professions when the joint project is over?

_ If «yes», what?

_ Can it be expected that the research effort as a whole will contribute to reducing the emigration of scientists from developing countries?

_ If «yes», what is the justification for this hope?

_ Are measures foreseen which will strengthen the partner institutions in the developing countries after the completion of the joint project?

_ If «yes», which?

_ Have preparations been made to enable the research to be continued after the end of the joint project, if necessary – even if it has to be done by one of the partners alone?

Appendix

Appendix 3: The Charter of North-South Partners

(The following is quoted from the paper by Jacques F. Gaillard, 1994: *North-South Research Partnership: Is Collaboration Possible between Unequal Partners?* Knowledge and Policy, 7/2, p. 58)

_ The collaboration should be based on a strong mutual interest and both parties should have something to gain from it.

_ Project proposals should, whenever possible, be drafted jointly and each partner should be associated as much as possible to the important decisions which need to be taken.

_ In particular decision on specific instrument purchase should be made jointly and the necessary provision for installation, maintenance and repair should be secured.

_ Provision should be made in the budget for a training component and research training should, whenever possible, take place as part of a formal degree program to increase commitment.

_ Salaries should be sufficient to ensure a full-time commitment, or completed by supplementary means (e.g. research honorarium) secured in the budget.

_ Transparence should be a golden rule between the partners, e.g. both sides have information on the budget allocations to each side and how funds are being spent.

_ Each cooperating group should include a substantial number of researchers (at least 3).

_ Both parties should meet regularly to review ongoing work and plan future activities.

_ Communication channels (e.g. fax and E-mail) must be available to secure efficient interaction between partners.

_ Scientific papers should be written jointly, with the names of the authors from both sides appearing on the published articles.

_ Collaborative programs should be evaluated on a regular basis, e.g., after each phase is completed. Monitoring should emphasise project outputs, rather than inputs.

_ Mechanisms should be established so that the collaboration can continue after the collaborative program is terminated to ensure a long lifetime to the collaborative partnership.

Epilogue

A draft version of these «Guidelines» has been widely circulated among colleagues both in Switzerland and abroad, so that they could offer their comments, criticism and advice. We were happy to see how many people replied, and we should like to thank them all here. On the whole, the comments were encouraging. Wherever it seemed appropriate, we have taken them into consideration in this final version. However, there were a few fundamental criticisms and questions that could not be worked into the existing text. We shall therefore discuss them as far as possible here.

One commentator raised some fundamental questions about the basic idea of promoting research in developing countries. For him, it is an important principle that «Poor countries do not deserve poor science» – and that doing good scientific research, especially research on basic questions, is becoming increasingly complex and difficult even in industrialised countries. But even when scientific quality is assured, the benefits of research are unpredictable, and not necessarily related to the project's goals. Investment in research that cannot be guaranteed to provide results that will be useful in practice within a reasonable period can be very high compared with the benefits, and it would be irresponsible for developing countries to invest resources in this way. Concentration on research also has other problematic results. One result of improving the training and qualifications of research workers is that they are in a position to become internationally mobile, and the resulting «brain drain» may result in a reduction rather than a strengthening of research capacity[20]. Apart from that, there is often an internal «brain drain», which draws well-qualified people away from their existing jobs in services or administration, where they have more urgent tasks to carry out. This argument deserves to be taken seriously, and we can sympathise with it – but it is up to each individual country to decide what its priorities are.

Several of those who sent suggestions felt that there should be some legitimation of this document, and for a statement about how authoritative it can claim to be. One asked for justification of the proposed method of doing research. Another said that the 11 principles in the «Guidelines» should be self-evident. Our answer is that the authors based their work on the one hand on what they have observed in their own experience of research in partnership with developing countries over the past decades, and on the other hand on statements by representatives of developing countries, for example at the Conference on Partnership held in Bern in 1996. They did not only express a need for the strengthening of the research capacity in their own countries, but also called for a code of conduct, which scientists – particularly those from Western countries – should follow in their relationships with colleagues in developing countries.

One comment that was made repeatedly about the Guidelines was that it would be difficult to put them into practice under the conditions that exist in the «real world». Points seen as particularly difficult were the change from multidisciplinarity to inter-or trans-disciplinarity; the transparency demanded of all parties; the possibilities of resolving conflicts, and the attitudes of some donors. Finding jobs for newly-qualified scientists could also be a problem under some circumstances. We need to repeat what was said in the Introduction; the aims expressed for each Principle are ideals; the decision as to how far they can be lived up to in practice must be left to those actually

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[20] Gaillard J. & Meyer J.-B., 1996: Le brain-drain revisité: de l'exode au réseau. In: Les Sciences hors d'Occident au XXème siècle, 7, 331-347, ORSTOM éditions, Paris

involved in projects. The Guidelines cannot offer any kind of guarantee; they are intended purely to offer help.

The present Guidelines do not claim to provide the final word on the subject of research in partnership. The fact that they have given rise to new questions and thoughtful criticism means that they do represent another small step on the difficult path that will have to be travelled by the international scientific community as the 20th century comes to an end. All those who want to come too, with an honest purpose and looking towards the future, will be heartily welcomed.

Abbreviations

BBW/FOES	Federal Office for Education and Sciences
CASS	Conference of the Swiss Academies of Sciences
EDA	Federal Department of the Exterior
EPFL	Swiss Federal Institute of Technology, Lausanne
ETHZ	Swiss Federal Institute of Technology, Z,rich
EU	European Union
IARC	International Agricultural Research Centre
IFS	International Foundation for Science
KFPE	Swiss Commission for Research Partnership with Developing Countries
NGO	Non-government organisation
RAWOO	Advisory Council for Scientific Research on Development Problems
SAS/SANW	Swiss Academy of Sciences
SAREC-SIDA	Swedish Agency for Research Cooperation with Developing Countries – Swedish International Development Cooperation Agency (SIDA)
SNSF	Swiss National Science Foundation
SDC	Swiss Agency for Development and Cooperation
TWAS	Third World Academy of Sciences, Trieste

Translation of the German version by J.M.Jenkins, Swiss Tropical Institute, Basel