
UNIT 4 ETHICAL ISSUES IN RESEARCH

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4.1 INTRODUCTION

Now we will look into ethical issues that need to be followed while carrying out any research. Ethics, which means rules of conduct or moral principles, gains importance when it comes to creating knowledge of any kind and specifically in the domain of research because the out come of research is directly influenced by the integrity of the researcher. In this unit we discuss how the issue of ethics in research evolved followed by research ethics in the field of Women's and Gender Studies. The unit next discusses the concepts and procedures related to research ethics. Lastly, there are case studies and points of discussion to make you understand how ethics becomes important while dealing with field situations. Let us now have a look at the objectives of the unit.

4.2 OBJECTIVES

After reading this unit you will be able to:

- Discuss ethical issues in research;
- Explain concepts and procedures related to research ethics;
- Outline field specific research ethics; and
- Explain importance of research ethics.

4.3 HISTORY OF ETHICAL ISSUES IN RESEARCH

Research ethics is a field which developed against the background of the Nuremburg trials held in 1945-46, at which several Nazi scientists, who had conducted inhuman experiments on Jewish inmates of the concentration camps, disabled, homosexuals and other persecuted groups, were tried. The discovery of the brutal methods adopted by these scientists shocked the world. This indicated the extent to which researchers could go, indulging in torture, ostensibly, in the pursuit of knowledge. This was a wake-up call to the scientific community, indicating the need to set down ethical rules for researchers that they must follow while conducting research. These rules were encoded in the **Nuremburg Code (1947)**, which lay down the directives for human experimentation. Its basic principles state that experiments cannot be conducted on any human being without his or her consent. Any experiment which can lead to disability or death is prohibited and no harm should come to a research subject. Risk of any kind associated with a study is acceptable only to the extent that it is compensated by the benefits expected from the research. The safety and consent of the research subject overrides all other considerations.

The Nuremburg Code is the basis of all subsequent ethical guidelines and protocols for research ethics. Several such guidelines have been adopted by various professional associations and research councils across the world, including India. In India, two significant ethical guidelines for research include the **Ethical Guidelines for Biomedical Research on Human Participants (2006)** issued by the Indian Council of Medical Research and the **Ethics Guidelines for Social Science Research in Health (2000)** issued by the National Committee for Social Science Research in Health.

At the heart of all these guidelines are some basic principles:

- Research is a voluntary activity that must be undertaken only when it is expected to lead to some benefit for humanity.
- It is not meant to serve the vested interest of any individual or group, whether it be, those conduct the research, those who commission it or those who sponsor it. If research has no other purpose than to benefit them, such research is unethical.
- Research on human beings cannot be conducted without their knowledge and consent. All human beings have the right to decide whether they would like participate in research or not.
- Any research which causes harm to any participant is not justified. Only in exceptional circumstances, harm that is minimal and inevitable and can be justified by the potential benefits of the research.

Let us now read about ethical issues related to research in the field of women and gender studies.

4.4 RESEARCH ETHICS IN THE FIELD OF WOMEN AND GENDER STUDIES

Over the years, in each field, there has been extensive discussion on research ethics focusing on their specific concerns and problems. This is also true of gender studies and women studies. The conscious and deliberate critique of science that is central to women studies, in particular, also has implications on ethics. The blurring of the boundary between the researcher and the researched is, in a sense, integral to the response to this critique of science.

The documentation of struggles and campaigns as also everyday experience by those involved in these events plays a very important role in the development of this field. As we have seen above, the ethics of research is based on a clear distinction between the researcher and the research subject and defines the obligations of the former and the rights of the latter. When these distinct categories do not exist, a reinterpretation of the principles becomes necessary.

Likewise, **feminist praxis** blurs the distinction between research and practice. There is no clear boundary between research as an activity and activism or developmental work. While it would be right to assert that all human activity needs to be governed by ethics, the ethical rules for research and practice are and need to be different. Research is an exercise undertaken for furtherance of knowledge. It is, in that sense, not imperative. However, action may be inevitable, imperative to preserve life, protect dignity and promote well-being. Thus, the ethical standards that one would employ to judge action would differ. Thus, it is often difficult to decide what standards to employ when judging any particular activity which combines research with practice.

On the other hand, there is an increasing awareness that, with the institutionalization of Women and Gender Studies in form of university departments and research centres, power and hierarchies have also begun to emerge. The gap between the woman academic and the woman research investigator is large. Just as the gap between those who occupy permanent positions in established institutions and those who are engaged in voluntary work or activism. The conventional roles and patterns of exploitation and appropriation of knowledge that were to be found when male scientists conducted research ON women are somewhat reproduced here. The benefits of research accruing to the main researchers in the form of research grants, career advancement and recognition may far outweigh the benefits accruing to the women who are employed as investigators in temporary contractual assignments or the ordinary women who provide the researchers with a wealth of information about the field, shape their perspective and facilitate access to the participants.

Thus, ethical considerations in research in this field centre on relationships and goals. We need to be concerned about the imbalance of power and control between the various players involved in research. Even if the roles of the researchers and research subjects are blurred, we need to be mindful of the fact that there may be an element of exploitation in the way people relate to each other, the manner in which decisions are made and the roles that people perform. Likewise, it is necessary to evaluate the nature of any activity to ascertain whether it is essentially action or research. This distinction should be based on a judgment of the essentiality and the outcomes of the activity. If any data gathering activity is largely serving to further knowledge and does not hold the promise of direct benefits to those involved, it would be more proper to apply the ethical standards of research. If any such activity is not essential, even though it may be useful, then it would be best to regard it not as research.

Check Your Progress:

i) What is Nuremburg Code?

ii) How are research ethics in Women's and Gender Studies different from other disciplines?

iii) Write basic principles that guide research in India.

4.5 ETHICAL PRACTICES IN RESEARCH

Apart from the larger ethical questions that are discussed above, researchers need guidance on how to deal with specific problems and adopt specific measures while conducting research. Some of these are outlined below.

4.5.1 Informed Consent

As stated above, the willingness of an individual or group to participate in research is an essential ethical requirement. This willingness must be based on full knowledge of what it means to participate in this research and freedom from any form of external pressure or constraints. Full knowledge would include knowing why the research is being done, who is doing the research, what one stands to gain from the research, what are potential risks associated with participation and what are the terms on which one can participate in the study.

Usually, this information is provided in a written form in a document called an **information sheet**, which is given to the participants. If they cannot read, it may be read out to them and explained. Some groups have also used innovative methods like group meetings, films, posters and role plays to convey this information. Any method which communicates this information effectively and provides space for the participants to clarify doubts, ask questions and make comments is a good method to use.

A useful checklist for drafting this document is as follows:

- **Name and description**

Name and description of the researcher/research team/organization should be informed to the participants. This should include names and contact details of all the key individuals involved, information about their legal status, their scope of work and any specific details that may be relevant to the study.

- **Description of the research**

This should include the goals of the study, where it is being conducted, who or what will be studied, how will they be selected, what kinds of questions will be asked, what other information will be recorded, how long will all this take and who will be involved in collecting all this information. If the research involves conducting any kind of experiments or observations or tests, this should also be explained clearly.

- **Risks and benefits**

All significant risks associated with the study should be explained. The concept of risks is explained in more detail below. While the risks need

not be exaggerated, they must also not be underplayed. Likewise, benefits, also explained in more detail below, must be reasonably stated.

- **Rights of the participants**

Certain basic rights are accorded to all participants. This includes the right to withdraw from the research at will, the right to protection of confidentiality and privacy (explained below in sub-section 4.5.2) and the right to know the findings of the research. Stating these rights explicitly in the research is essential and amounts to a written assurance by the researcher that they will fulfill their obligations to the participants.

Box No. 4.1

An information sheet containing all these components must be given to the participants. Following this, an informed consent form may be signed by the participant. This consent form states that the participant has understood the nature of the study and the implications of participation and accepts these conditions. An informed consent form is, in a sense, a contract, which documents the agreement between the researcher to fulfill certain obligations and the participant to provide information/data for the study. In our context, where not everyone is literate, the written consent form may be countersigned by a witness, who endorses the fact that the entire informed consent procedure was followed. Occasionally, a written consent may not be taken because doing so may put the participant in some kind of problem. This could be because the participants are engaged in some unlawful activity or are in a very vulnerable situation where discovery of their involvement in research could invite harm. However, as a rule, such conditions are rare and need to be carefully assessed. Several other variations of this consent procedure also exist. This includes audio-recording or video-recording of the entire informed consent procedure.

In certain circumstances, where information/data which has already been gathered is being used and that cannot be traced back to the individuals to whom it belongs, informed consent requirement may be waived.

4.5.2 Privacy and Confidentiality

This concept derives from two principles;

The respect for a person's dignity and the obligation to prevent harm. It essentially means that all information which could identify a person which is received during the research process must be protected and not shared with anyone outside the research team. There are two aspects to this concept. Firstly, it means that data gathering must be done in conditions where participants have privacy. The researcher must ensure that they

cannot be overheard. In some cases, it may be important to ensure that the participant is also not seen giving an interview or participating in a discussion. In many cases, particularly, in research studies conducted in closed institutions, there may a need to keep the identity of those who refused to participate in the study, also secret. In such cases, even the informed consent procedure must be conducted in complete privacy.

In addition to this, respecting privacy also means that the researcher must **respect boundaries laid down by the participants** and not intrude into areas beyond the scope of the research. This may mean that they must not approach participants outside certain spaces. They must not attempt to eavesdrop or spy on participants. They may, during the course of the study, become privy to information about the participants through other sources, but they should not use this as data. They should not also use this information to interrogate participants.

Secondly, **information gathered from the data** collection process must be kept **safe** and must **not be** shared with anyone outside the research team. This may require that paper records are kept under lock and key. Digital records may be stored with password protection or encrypted. Further, researchers are required to ‘**anonymise**’ data, which means that all identifiers such as names, addresses, details of personal history which could lead to identification of that individual are removed and replaced either by acronyms or pseudonyms. Such practices enhance the safety of data and ensure that confidential information about participants is not unwittingly revealed. Apart from the data, while reporting the findings too, care must be taken to avoid details which could lead to identification of the participants. This means that specific individual details which are not relevant to the study must be omitted. Findings may need to be presented in aggregate form when disaggregation may lead to revealing the identity of an individual participant, an institution or a community. Certain exceptions are permitted. Such as:

- When the information is already in the public domain and pertains to a public figure, names may be mentioned.
- When a participant or group of participants explicitly states that they want their identity to be stated, the researcher may choose to state their identity.

Box No. 4.2

As a general rule, researchers must evaluate the harm that may come to the participants if their identity is revealed; greater the harm, more the safeguards that they should adopt, to prevent breach of privacy and confidentiality

4.5.3 Risk and Harm

As we have seen, one of the most important ethical requirements for research is that it should not endanger participants in any way. No scientific achievement is great enough to justify deliberate injury or harm caused to research participants. Thus, in every study, it is important to assess what risk it poses to the participants. These risks may be of varied kinds. At its most fundamental level, it may be a risk to the life and health of the participant. At another level, it may be a risk of financial and material loss. This may be in the form of **wages lost, cost of travel and stay, cost of hosting** the research team, **loss of production** due to inability to devote adequate time to their work.

Research may also pose the risk of **stigmatisation** and **discrimination**. When it is known that a particular study involves only certain kinds of participants e.g. those suffering from a certain disease or those engaged in a certain activity, those who participate in the study would get identified. Stigmatisation and discrimination may also result from the manner in which findings are reported e.g. when certain clandestine practices prevalent in a particular group or among particular individuals are revealed. Risks may also be emotional. Certain research studies which focus on topics such as violence, abuse or other traumatic experiences may compel participants to relive painful experiences. Some studies may force them to reflect on problems that they find difficult to confront.

A researcher must assess beforehand what risks are associated with a study and what can be done to minimize them. Some measures to change the study design, the data collection procedures, and better training of the research team could very effectively address these risks. In a study, where inherently the risks are very high, the researchers must consider putting in place safeguards, remedial measures and reparation for those who are affected by the research. These could be in the form of monetary compensation, counseling support, access to medical and psychiatric care, information and education and linkup to support facilities such as voluntary organizations, legal aid and welfare services.

Harm is actual injury of any kind caused to a participant. This, again, could be **physical, financial, social** or **emotional**. In most cases, harm is not deliberate. However, the failure to assess risks, make attempts to minimize them, and put in safeguards to deal with situations and problems that could have been predicted is negligent and unethical. In some cases, harm may befall on participants despite the best efforts of the researcher. In such cases, those harmed must be suitably compensated. Firstly, all attempts must be made to alleviate their suffering and, secondly, appropriate

compensation in cash, kind or services must be made. There is a valid space for ascertaining the degree to which the researcher or the research study is responsible for the harm caused. It may also be that either that harm was inevitable and would have befallen the participant in any case. In some cases, the participants' own actions may have contributed to the harm. Regardless of cause, as a basic principle, researchers must recognise that participants voluntarily contribute their time, make them vulnerable and put themselves at risk for the sake of research. Thus, it is only fitting that, at the very least, researchers make all attempts to alleviate their suffering.

4.5.4 Benefits

By benefits, we refer to those **which accrue to the research participants and to society at large**. As discussed earlier, the relevance of a research study is determined by the extent to which it contributes to the public good. This contribution may be in terms of useful knowledge, innovations and inventions, goods and services. Some studies may provide direct benefits to the participants in the form of goods and services. Other direct benefits may include education and skill development which may enable participants to enhance their well-being. Other benefits may be collective, such as access to networks, assistance for resource mobilization, publicity, which enables that collective to achieve its objectives. Some studies may not result in any tangible benefits, but serve an emotional or ideological need. They may provide participants with an opportunity to voice their feelings, share their experiences, reflect on their situation and become more aware. While, in general, benefits accruing to participants are viewed positively, in some circumstances they may be regarded as inducements. A benefit which is large enough to make a participant ignore the risks associated with a study is termed as an inducement. The quantum and type of benefit, which may serve as an inducement, differs from context to context. For those participants who have no access, for e.g. to medical services, the promise of free treatment may serve as an inducement. In another context, teenagers, who are otherwise ignored and not consulted by adults, may feel induced to participate in a study without understanding its objectives, simply because there is someone who wants to listen to them. In all cases, the researcher must make a judgment about where to draw the line.

Apart from the benefits that accrue directly to the participants, **research produces benefits for society**. It may add to the body of knowledge, it may provide evidence about the outcomes of programmes, it may provide useful explanations for phenomena and events. Oftentimes, this benefit is realized only in the long term. **Those conducting the research may not be in a position to assure the realization of these benefits**. There may be a long

process of public debate, consensus building, policy making or translation required to transform the findings of any research into tangible benefits. This kind of research is also very important and relevant. However, in order to be useful, it must be well designed, rigorously implemented and extensively disseminated. Research, which is not made public, most often, does not serve a useful purpose. Moreover, it is the duty of a researcher to ensure that the findings of all research, which can be validated, should be put in the public domain, whether they are positive or negative. This is particularly so, when research findings do not conform to the expectations of the researcher or reveal uncomfortable truths.

4.5.5 Integrity

Another set of concepts in ethics pertain to the 'intentions' of the researcher rather than his or her actions. Integrity, as the word supposes, is about being honest and forthright. There are several aspects of research in which no ostensible harm comes to any participant, but a wrong is committed. This may be due to several reasons.

- **Conflict of interest:** This is a situation in which two or more roles of an individual conflict with each other and can bias the researchers' perspective. Several forms of conflict of interest exist e.g. an organization may be interested in showing that their programme succeeded and may, therefore, decide to conduct the evaluation themselves or nominate a researcher who is biased towards it. A researcher may be involved in advocacy and campaigns and wants to conduct research to validate her stand. A researcher may be tempted to alter the design of the study or the interpretation of results if she stands to gain financially or professionally from doing so. It is impossible to eliminate all forms of conflict of interest, but being aware of them and making them explicit is essential. In conditions where the conflict of interest is serious enough to damage the credibility of the researcher and influence the conduct of the study, the researcher must give up one of the competing roles. Alternatively, s/he must withdraw from the research.
- **Fraud:** This refers to any form of manipulation of the data. It includes fictitious data generation (called fabrication), selective recording of information, tampering with test results and findings. All forms of fraud are unethical.
- **Plagiarism:** Plagiarism includes using someone else's work without according credit to that person. The most common form of plagiarism is using someone else's published or unpublished writing and claim authorship. Oftentimes, the plagiarized material is not from one source alone, but compiled from various sources. Citing passages from other

texts without references is also plagiarism. Other forms of plagiarism include using unpublished data belonging to someone else for analysis and writing. Often, students placed for internship at an institution get access to the records of e.g. patients/clients of an institution and use them for research without permission or acknowledgement. All such forms of plagiarism must be prevented.

4.5.6 Mechanisms for Regulating Research

While **self-regulation** by the researcher is imperative to the ethical conduct of research, there are also institutional safeguards in place. The primary institutional measure for ethics regulation is a research ethics committee or an institutional review board. These are autonomous bodies nominated by the institution to review all research being conducted in a particular institution to ensure that it meets the basic ethical standards. Some ethics committees are not attached to any institution, but function independently. They may review protocols for a fee.

Such bodies are usually present in institutions which conduct biomedical research. In India, social science research is not so regularly reviewed by **Research Ethic Committees (RECs)** or **Institutional Review Boards (IRBs)**. However, of late, more and more universities and research institutions are instituting such bodies to review research, both conducted by the students and by the faculty. While such bodies may differ in composition, periodicity of meetings and procedures but, they must meet certain criteria. They must be headed by an external person, not connected in any way to the organization. It must be multi-disciplinary, having members from various disciplines, and from law and philosophy. There should be at least one member who can represent the participants. The minimum number of members should be five. Of these, external members not connected to the institution must be in a majority. The proceedings of the meetings of the REC/IRB must be formally documented and filed. It is necessary to protect the confidentiality of the discussion, but decisions of the RECs/IRBs must be made available to all in the organization. If there is a member whose own study is being reviewed, then that person must withdraw from the discussion. Generally speaking, RECs arrive at decisions by consensus. However, in case consensus is not reached, a vote is taken.

In the last section of this unit you will read about a two case studies and look into ethical issues involved. But before that, attempt the following questions to assess your understanding.

Check Your Progress:

- i) *List ways of collecting informed consent from the participants.*

- ii) *What is the check list that should be handed over to the participants of any research?*

- iii) *How can a researcher safeguard ethical issues in her/his research?*

Case Studies:

An important method for developing a better understanding of ethics is by using case studies. Given below are 2 case studies which you may discuss in a small group. Certain key questions have been given at the end of each case study to facilitate discussion.

(Source: These case studies are based on Unit-writer's own experiences as member of research and ethics committees and fictionalised).

Case Study 1

Two different approaches to provide protection and care to young participants

A doctoral student of Indian origin registered at an American University was doing her research on sexuality of young unmarried women in the age group of 18-24 years. The site of the study was in an Indian city where a local organization was undertaking a larger intervention research study on young people's sexual and reproductive health. This organisation also had other long-standing programmes in the same area. The understanding between the student and the organisation was that the latter would provide access and logistical support to the former. All the fieldwork would be conducted by the student herself, who was familiar with the local language and milieu, having spent her childhood in India.

The study involved semi-structured interviews with randomly selected young women in a specified geographical area, which was part of the intervention area of the local organisation. The questionnaire was quite general, covering aspects such as menstrual hygiene and health, body literacy and body image, knowledge of sexual and reproductive health, morbidity and use of healthcare and a few questions on sexual behaviour. While there was no specific component of questions on abuse, for those women who reported any form of abuse, an additional set of questions would be asked.

The study was first reviewed by the research ethics committee of the university where the student was registered for her Ph.D. The committee opined that the subject matter of the study would be considered sensitive in the Indian context where there is a strong taboo on discussion of sexuality of unmarried women, as they are expected to be sexually inactive. Given this, the highest level of confidentiality should be maintained; the names of the respondents should not be recorded in any form in the questionnaire. The student was also advised to ensure that the staff of the local organisation was not involved in the data collection and did not obtain access to any confidential information as they resided in the same area. The student was advised to provide information about existing support services to participants who requested help. The university's research ethics committee approved the study, conditional to approval by a local ethics committee.

As the local organisation did not have its own ethics committee, the student approached an independent ethics committee located in the same city. She also submitted the decision of the university's ethics committee as a part of her application. The members of the independent ethics committee included one public health physician and one social worker. Both had several years of experience of working in the discipline where the student's research was to be conducted. The ethics committee opined that the study involved

a very vulnerable group who, being unmarried, had very little access to sexual health services; and being women, had very freedom in their own families. Thus, this study would offer them a rare opportunity to discuss their sexual health problems and also speak about abuse. The ethics committee also noted that the organisation hosting this student had the necessary resources to provide support and care to those women who may be in need of it. Another concern expressed by some of the members was that the student would be leaving the country in a few months and would not be there to deal with any adverse events related to the study—such as intimidation of participants, emotional trauma and negative outcomes—which may result from the participants' efforts to seek help based on the information provided by the student. In their view, the local organisation was the most suitable and responsible body to ensure the protection of the participants and provision of care. The ethics committee ruled that the student should record the names of the participants and maintain a database which she would share with the local organisation. It also asked the student to give access to the data of any specific participant to the local organisation on their request. The ethics committee asked the student to obtain a written commitment from the local organisation that it would provide medical care, referral services and social support to those participants who may suffer any kind of adverse event during the study or seek help from it. The organisation readily agreed to give such a commitment.

The student was left in a quandary with two completely contrary decisions by her university research ethics committee and the local ethics committee.

Discussion Questions

- 1) Do you agree with the argument of the local ethics committee that the research by the student offered the best opportunity to young women to discuss their sexual health and abuse? Why?
- 2) What are the pros and cons of the reasoning of the local ethics committee in ruling that the student record names and addresses of the participants and share that database with the organization working in the community?
- 3) If you were a member of the ethics committee in USA that reviewed the student's proposal, would you accept the commitment given by the local community organisation? Why?
- 4) Suggest ways in which the different standpoints of the ethics committees could be reconciled.

Case Study 2

Women and TB

R is a women's organisation working in a moffusil town, largely through micro credit and finance. After nearly a decade of working with women, they begin working with adolescent girls. They start a non formal school for girl dropouts. This school becomes quite successful and draws girls from the poorest localities of the town.

In the meanwhile, the town's municipal corporation receives aid from a funding agency to pilot a project for setting up DOTS centres in non-clinical settings. The strategy is quite simple. The corporation's TB workers identify persons having symptoms of TB through community visits and house-to-house contacts. They arrange for them to be taken the district hospital for investigation. Treatment regimen is decided and the entire supply of drugs (for 6 or 9 months as appropriate) is given to a local organisation. This organisation has the responsibility of running a half-day centre, where patients can come and take their daily drug dose. This organisation also follows up with those patients who are defaulting on treatment. The government TB worker monitors the work of the centre. No grant or remuneration is provided. Organisations are invited to participate in this programme merely in the interest of promoting good health.

The municipal corporation approaches organisation R to set up such a centre. The school provides an ideal location (being situated right in the middle of the town). Due to the presence of the school, the place is always open from 10 a.m. till 2 p.m. At the same time, as the micro credit activities are also conducted from the same premises, there are always people moving in and out. This provides a great deal of anonymity to the patients, even while being easily accessible. Apart from this centre, the municipal corporation also sets up four other centres in public places—like the market, *Zilla Parishad/Panchayat* office, etc. Being a small town, there is not much difference in the physical accessibility of the centres.

After a year, a review of patient records is done by the municipal corporation, which shows that nearly two thirds of the patients enrolled in R organisation's centre were female. Even more surprisingly, one third of the patients are adolescents between the ages of 13-18 years. This profile is completely different from that of patients from the other centres -which seem to have largely men and children as users. The programme funders (who are also involved in research on TB) are very enthusiastic about these findings. In their programmes world-wide, they have been finding it very difficult to bring women, in general, and adolescent girls in particular into the programme. They send a team of experts to document the experience of this centre and develop a blueprint for scaling up this experiment. The team decides to conduct in-depth interviews with the patients and their

families to understand from their perspective, what makes this centre more accessible than others.

During the scientific review meeting, it is pointed out that merely using the clinic data and interviewing patients would not give an idea about the actual reach of the centre. The reviewers suggest that it would be important to find out what proportion of the women and girls in the community who are infected are actually accessing services. Since there are no accurate statistics about the local prevalence of TB, the team also decides to conduct a household survey in a two-square kilometre area around the centre to estimate prevalence. The survey consists of administering a questionnaire containing a checklist of symptoms, followed by a clinical examination of those having symptoms and giving consent, and lab investigations.

The municipal corporation TB worker takes this study team (which consists of a clinician, an epidemiologist and an anthropologist) to meet the management of the organisation R. When informed about their intentions, the director of R becomes very anxious and circumspect. She refuses to cooperate with the team, saying that their agreement with the corporation did not include the provision of such assistance. Besides, she states, that she does not think it is right to invade the privacy of the patients. The team offers a compromise by saying that they would conduct the interviews in the centre itself, rather than the houses of the patients. However, she also rejects this suggestion. She feels that this would entail singling out students and visitors, which would make their TB status very obvious to others. This would be more so because the same team would be conducting a household survey simultaneously with this qualitative study. Many of the patients have not even revealed to their families that they are seeking treatment for TB and hence would not like their families interviewed.

This leads to an impasse and a stormy argument ensues. The expert team blames the Director for perpetuating the stigma associated with TB by building so much secrecy around the issue. They also accuse her of patronising her clients and taking decisions on their behalf. They suggest that, instead, she should be encouraging the women and girls to dialogue and communicate with their families and community so that the stigma around TB is combated. The Director, on her part, argues that the majority of the patients at her centre are poor women, who are struggling to make ends meet. The others are young girls from vulnerable families who have struggled a lot to be able to come to school. Her first priority is ensuring that they get treatment and survive. Apart from the stigma against TB, women and girls have many other battles to fight. She also accuses the team of being insensitive to the local culture and imposing their world-view on her patients. Sarcastically, she suggests that they take their study to a corporate hospital and see how much cooperation they get from the hospital management and the rich patients there. She thinks it is patently unfair that the onus of changing the

world should also be put on the poor. Alarmed by the heated arguments and the possibility of a scandal, the municipal corporation itself sabotages the study by refusing to part with any information from the patient records, which are in their custody.

Discussion Questions

- 1) Do you think that the rationale for the proposed study was justified? If so, what are the key ethical issues that emerge in this study?
- 2) The researchers (who also represent the sponsors) and the Director, as gatekeeper, have raised some issues related to the larger politics of gender and class. What do you feel about their respective positions?
- 3) Do you think that the municipal corporation was justified in preventing the study from being conducted? If you feel otherwise, what is the methodology that should have been followed?

Following is the summation of what you have read in this unit.

4.6 LET US SUM UP

This unit began with the evolution of ethical issues in research which started with Nuremberg Code in 1947 with the laying down of directives for human experimentation. In India two important bodies regulating ethical guide lines and protocol in research are functional. One of them regulates the issues in bio-medical research and the other one looks into ethical issues in social science research. The unit that delves into research ethics specific to the field of women's and gender studies especially because this field blurs the boundary between the researcher and the researched. Thereafter, there is a discussion on the various ethical practices that need to be followed while carrying out research namely, informing the participants about the aim of the research and its description, risks and benefits to the participants, researcher and the society at large. Other aspects like privacy, confidentiality and intention of research should be shared with the participants. The unit ends with discussing two case studies.

4.7 UNIT END QUESTIONS

- 1) What is ethics? Discuss in the context of research.
- 2) Explain how research ethics are different in the field of women and gender studies?
- 3) Discuss various practices to address the ethical questions in research with regards to research in this discipline.

4.8 REFERENCES

Indian Council of Medical Research (2006). *Ethical Guideines for Biomedical Research on Human Participants*, http://icmr.nic.in/ethical_guidelines.pdf (Last accessed on 2 May 21, 2014)

National Committee for Ethics in Social Science Research in Health (2000). *Ethical Guidelines for Social Science Research in Health*. Mumbai: CEHAT

Jesani Amar and Barai Tejal (eds). (2005). *Ethics in health research, a social science perspective*. Mumbai: Centre for Studies in Ethics and Rights.

Contractor Qudsiya (2008). *Fieldwork and social science research ethics*, in Indian Journal of Medical Ethics, Volume 5, no 1, January-March 2008 <http://www.issuesinmedicalethics.org/pdfs/index.php/ijme/article/download/..../1124> (Last accessed on May 21, 2014).

4.9 SUGGESTED READINGS

Jesani Amar and Barai Tejal (eds). (2005). *Ethics in health research, a social science perspective*. Mumbai: Centre for Studies in Ethics and Rights.

Contractor Qudsiya (2008). *Fieldwork and social science research ethics*, in Indian Journal of Medical Ethics, Volume 5, no 1, January-March 2008 <http://www.issuesinmedicalethics.org/pdfs/index.php/ijme/article/download/..../1124> (Last accessed on May 21, 2014).