

# Doing Ethical Research

By  
Tejal Barai<sup>1</sup>

Social scientists today research areas that are not only very personal and intimate, but also very sensitive. New and innovative methods are devised to get the information sought. This is done in order to get the valid and the maximum possible information. However, what we should not forget in the process is the very subtle fact that the entire process of doing research and seeking information can be traumatic to those giving such information, i.e. the subjects or the participants of research. Thus the ethics of research is vital in doing any kind of research.

The National Committee for Ethics in Social Science Research in Health (NCESSRH), with its coordination and research secretariat based at CEHAT, has evolved a document, “*Ethical Guidelines for Social Science Research in Health*”<sup>2</sup>. The guidelines are not only evolved by a committee of experienced social scientists<sup>3</sup>, but it also has incorporated the feedback received from a very wide community of researchers from across the country. This was made possible since the draft of the above was presented and discussed at a National Meeting held specifically for this purpose and attended by over 60 researchers. The ethical guidelines thus have received a wide consensus and appreciation.

The document, it was agreed at the meeting, has certain very basic values and concepts that can be applied to a wide variety of research areas including inter-disciplinary research. For instance, what should be some basic minimum guidelines for doing social science research involving patients who are HIV positive? The research area not only being sensitive, carries with itself a social taboo. It thus needs to be handled very sensitively. Moreover, their right to informed consent and privacy should be protected. Informed consent with patients with AIDS poses some problems with researchers. How does one get identify them? At one of the presentations that the author had given to seek feedback on the draft guidelines, a researcher admitted that she was given free access to hospital records listing HIV positive patients. While this raises the issue of the confidentiality of such records, it also highlights the problems faced by researchers. Keeping with the spirit of the ethical guidelines, the best possible way could then be to ask the hospital authorities, the person in charge who is already acquainted with the patients, to make the first contact. The patients should be given information about the study and made aware of their rights. Only when the patients has consented, should the names be passed to the concerned researcher. It is then the responsibility of the researcher to not only take the consent of the patients again, but also to conform to the ethical guidelines laid down. This would include, ensuring privacy at the time of data collection and an ethical and sensitive reporting of such information. Utmost care should be taken to protect the anonymity of the research participants as well as the confidentiality of the information collected<sup>4</sup>. The participants should also not be subjected to undue stress. Post – research counseling is also very essential since the experience to participating in research could prove traumatic to them.

Moreover, it should be noted that the guidelines are not used mechanically nor should they be used as a one step agenda. While it is important that researchers plan their studies in accordance to the guidelines, it is also important that the researchers continue to maintain ethical sensitivity and consciousness throughout the entire course of the study.

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<sup>1</sup> Tejal Barai is a researcher with CEHAT and member of the coordination and research team of the NCESSRH

<sup>2</sup> For a copy of the revised and final guidelines, write to Ms. Tejal Barai at [cehat@vsnl.com](mailto:cehat@vsnl.com).

<sup>3</sup> Ghanshyam Shah, Manisha Gupte, Sarojini Thakur, Ashok Dayalchand, Lakshmi Lingam, Padma Prakash, V R Muraleedharan, Geetanjali Misra, Radhika Chandiramani, Thelma Narayan; Coordination and Research – Amar Jesani and Tejal Barai.

<sup>4</sup> Please refer to the document, *Ethical Guidelines for Social Science Research in Health* for a more detailed guide on ethics in research.