Ethical research is grounded in quality data: a clinical data management workshop in Varanasi

PARITOSH MALAVIYA1, RAFFAELLA RAVINETTO2, SHYAM SUNDAR4

1 Head, Data Management Unit, Institute of Medical Sciences, Banaras Hindu University, Varanasi INDIA e-mail: paritosh.malaviya@yahoo.com, 2 Head, Clinical Trials Unit, Institute of Tropical Medicine, Antwerp BELGIUM e-mail: ravinetto@ihg.be, 3 Professor, Department of Medicine, Banaras Hindu University, Varanasi INDIA e-mail: drshyamsundar@redmail.com

Research ethics is closely related to scientific and methodological standards. A research project involving human participants is never ethical if it is not scientifically and methodologically sound in the first place. Clinical data management, despite often being perceived as "just" a technical methodological service, plays a fact a key role in ensuring that data collected within a medical research are true, accurate and reliable; that subjects' privacy and confidentiality are duly ensured, and that the study findings will serve the interests of individual and public health.

In order to share analyse the challenges faced by clinical data managers engaged in North-South and South-South collaborative medical research, a meeting was organised in Varanasi on March 4-8, 2013, by the Banaras Hindu University together with the Institute of Tropical Medicine in Antwerp (Belgium), in the framework of the Switching the Poles network, Association for Data Management In the Tropics (http://admit.org/). The workshop was funded by the development agency, Belgian Technical Cooperation.

The meeting was attended by 18 participants from India, Nepal, Cambodia, Benin, Burkina Faso, the Gambia, Ghana, Kenya, Malawi, Rwanda, Belgium and the UK. The group spent five days together, sharing experiences from the different countries and settings, and trying to find together answers to the most frequent challenges they face. Such challenges are mainly due to the constraints in financial or human resources allocated to non-commercial research; the limited availability of appropriate tools and technologies, especially when working in remote research sites; and the lack of harmonisation, especially in multi-site research, or when pooling data from different research projects.

[1132]

Publisher's Note
Form IV (See Rule 8)

1. Place of Publication: FORUM FOR MEDICAL ETHICS SOCIETY
   0-18 Nav Bhawna Premises Co-op Society,


3. Printer’s name: Dr Sanjay Nagral
   Nationality: Indian
   Address: FORUM FOR MEDICAL ETHICS SOCIETY
   0-18 Nav Bhawna Premises Co-op Society,

4. Publisher’s name: Dr Sanjay Nagral
   Nationality: Indian
   Address: FORUM FOR MEDICAL ETHICS SOCIETY
   0-18 Nav Bhawna Premises Co-op Society,

5. Editor’s name: Dr Amar Jesani
   Nationality: Indian
   Address: FORUM FOR MEDICAL ETHICS SOCIETY
   0-18 Nav Bhawna Premises Co-op Society,

6. Name of Owner
   Address: FORUM FOR MEDICAL ETHICS SOCIETY
   0-18 Nav Bhawna Premises Co-op Society,

I, Dr. Sanjay Nagral, hereby declare that the particulars given above are true to the best of my knowledge and belief.

Sd/-
31 March 2013.