

Brief Summary – 5th GFBR meeting

**22-23 April 2004
PARIS , FRANCE**

The theme of this forum was "Sharing the benefits from research in developing countries: equity and intellectual property." The conference unfolded in three sessions: general discussion, case studies, and technical talks. During the meeting, several themes emerged regarding the conference topic: The need for collaborations and partnerships between stakeholders in the North and the South; the need to respect traditional practices and social structures; the need to consider the complexities of community involvement in research; and finally the need to consider benefits not only in terms of financial gain, but also in terms of the development of capacity, knowledge, experience and autonomy.

General discussion

During the presentations and discussions, Jean-Claude Ameisen stressed the need of ethics to evolve with scientific progress and the importance of broad-based social discussion about ethical issues. Mario Stasi warned against conducting research that does not benefit the host community and country but only benefits Northern countries, and stressed the need to address post-trial access of product for participants and involved communities. Thereafter, speakers discussed the complexity inherent in defining a community and through this, the representation of community interests. Community could be defined from different aspects, including spatial, spiritual, political and sociological dimensions. Therefore, different representations of the same community could have different interests, which may induce conflict of interests. So, how to choose the most ideal representation of a community? Dr. Derme recommended that researchers should be particularly careful in establishing "equidistance" from different interest groups in order not to polarize communities with competing interests. Communities must define their community on their own terms, and not leave it for outsiders.

The debate focused next on the sharing of the benefits of research. First discussion centered on the double meaning of the word "sharing" in different settings: It can mean dividing up resources on the one hand, while it can refer to uniting together on the other hand. Dominique Lecourt put forward the argument that the field of science and medicine is becoming increasingly competitive, and hence called for more humanistic notion of sharing in the context of research. As to how to operate benefit-sharing, Ambrose Talisuna advocated that many international guidelines employed the principle of "reasonable availability." This is difficult to be applied in practice, especially for research that does not create products, such as basic genetic research or epidemiology studies. Therefore, he held out three criteria for determining how to conduct benefit-sharing, i.e., benefits should be fair; collaborative partnerships are needed; and transparency is required.

Case studies

Four cases were discussed during the conference. Two concerned research on traditional medicinal plants. Participants raised the concern that developing countries hosting research, or indigenous groups within these countries, might not benefit sufficiently from the results of the research. Discussants underscored that indigenous people should have legal and political representation to negotiate with the research sponsor in terms of the structure and design of the research project, after wide consultation with the community. Participants also considered that besides monetary benefits, benefit sharing should cover protection of indigenous cultures and customs, as monetary benefit could be beneficial or harmful. One meeting participant remarked that indigenous communities have the moral obligation to share medicinal knowledge which may help others: knowledge should be differentiated from intellectual property. Participants felt there was difficulty in addressing fair benefit-

sharing, due to the complexity of deciding if the knowledge existed in the public or the private domain, ascertaining the legitimate holder of the knowledge, and uncertainty about whether the knowledge would result in any monetary profit.

The other two cases related to genetic research. Discussants of these cases realized that differences in history, scientific infrastructure and familiarity with science, the degree of democratic representation, and religious affiliations between the hosting and the sponsoring countries all should be taken into account when conducting genetic research in developing countries. Discussion of the genetic research focused on questions of ownership, shared heritage, confidentiality and identity. The populations from which genetic samples were taken does not necessarily constitute ownership in the sense of legal or political control, and in the context of research, access to samples is more relevant than ownership of the samples or genetic data. In genetic research, it is often difficult to determine the boundaries of group interests and individual rights. Thus, questions were raised: how to measure the benefit, who has the authority to consent to genetic research, and what is the potential social value of the genetic databases?

Technical talks

In this session, Cristina d'Almeida underscored the importance of national governments in establishing intellectual property agreements and manufacturing capacity to benefit their own populations. Dr. Kilama highlighted the importance of political context, national laws and authoritative bodies, and the relationships between and among different communities and national governments under which the research is carried out. He also stressed the importance of knowing the relationship between the groups in authority and the community, and understanding the relevance of trust or the lack of trust between different stakeholders.

Conclusion

Throughout the 5th GFBR, participants called for partnerships among and between different stakeholders from both the South and the North, and agreed that an effective partnership should consist of good-faith negotiations of research design before commencement of the study, respect for traditional practices and social structures, and transparency throughout the research process. However, participants acknowledged the challenges in determining proper representation of the community, and stressed the need to consider other forms of benefits besides monetary gains. Examples were gains in capacity, knowledge, experience, and autonomy. Delegates also acknowledged the complexity of community structures, and the relationship between traditional medicine and modern medicine. They highlighted the importance of understanding the relationships between different stakeholders both in developing and developed nations, with particular stress on fair, collaborative and transparent procedures.