



Ethical Issues in Governing Biobanks: Global Perspectives

Nikola Biller-Andorno, Alexander M. Capron

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Population genomics research drawing on genetic databases has expanded rapidly, with some of this information being combined in 'biobanks'. Managing this information in an appropriate way is a highly complex ethical issue in the health policy arena. This book combines theoretical and empirical research to analyze the areas of conflict and consensus in the regulatory and ethical frameworks that have been developed to govern biobanks. Ethicists from the Department of Ethics, Trade, Human Rights and Health Law (ETH) of the World Health Organization, the Institute of Biomedical Ethics of Geneva University and the Institute of Biomedical Ethics of the University of Zurich, with the support of the Geneva International Academic Network (GIAN), examine the conditions under which genetic databases can be established, kept, and made use of in an ethically acceptable way. In addition to a comprehensive review of the scientific literature and a comparative analysis of existing normative frameworks, they present the results of in-depth interviews with experts around the world concerning the most unresolved and controversial issues. The results of that study, combined with their normative analysis, leads to recommendations for a better international framework.

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