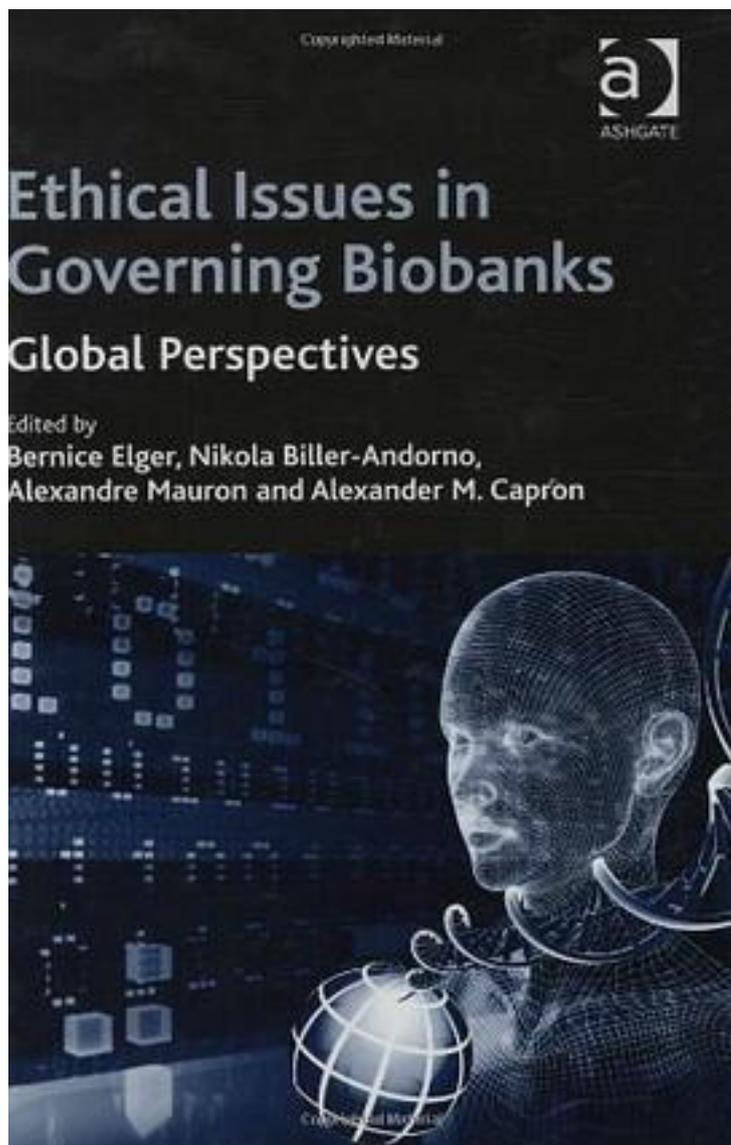


Ethical and Regulatory Aspects of Human Genetic Databases



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Population genomics research drawing on genetic databases has expanded rapidly in recent years. In some cases, this information has been combined with details on individuals' health, lifestyle or genealogy. Protecting the data available from such databases has consequently emerged as a highly complex ethical issue in the health policy arena. This book combines theoretical and empirical research to discuss the development of an international regulatory framework to provide practical guidance. In this volume, the Geneva International Academic Network (GIAN), the Department of Ethics, Trade, Human Rights and Health Law (ETH) of the World Health Organization, and the Institute of Biomedical Ethics of Geneva University have joined together to study the conditions under which genetic databases can be established, kept, and made use of in an ethically acceptable way. The work includes a comprehensive review of the scientific literature along with a comparative analysis of existing normative frameworks. Unresolved and controversial issues are taken up in empirical studies and the results combined with analysis to produce draft recommendations towards an international framework. The book will be a valuable resource for researchers and practitioners working in the development, maintenance and regulation of biobanks.

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