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Comparative Issues in the Governance of Research Biobanks: Property, Privacy, Intellectual Property, and the Role of Technology

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In the last few years, the boom in biobanking has prompted a lively debate on a host of interrelated legal issues, such as the Gordian knot of the ownership of biological materials, as well as privacy concerns. The latter are due to the difficulty of accepting that biological samples must be completely anonymous without making it practically impossible to exploit their information potential. The issues also include the delicate role and the changing content of the donors informed consent as the main legal tool that may serve to link the privacy and property interests of donors with the research interests and the set of principles that should be at the core of the biobanking practice. Lastly, the IP issues and the patentability of biological samples as well as the protection of databases storing genetic information obtained from the samples are covered. Collecting eighteen essays written by eminent scholars from Italy, the US, the UK and Canada, this book provides new solutions to these problems. From a comparative viewpoint, it explores the extent to which digital technology may assist in tackling the numerous regulatory issues raised by the practice of biobanking for research purposes. These issues may be considered and analyzed under the traditional paradigms of Property, Privacy, Informed Consent and Intellectual Property.