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Ethics, Law and Governance of Biobanking: National, European and International Approaches (The International Library of Ethics, Law and Technology)

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Biobank research and genomic information are changing the way we look at health and medicine. Genomics challenges our values and has always been controversial and difficult to regulate. In the future lies the promise of tailored medical treatments and pharmacogenomics but the borders between medical research and clinical practice are becoming blurred. We see sequencing platforms for research that can have diagnostic value for patients. Clinical applications and research have been kept separate, but the blurring lines challenges existing regulations and ethical frameworks. Then how do we regulate it?

This book contains an overview of the existing regulatory landscape for biobank research in the Western world and some critical chapters to show how regulations and ethical frameworks are developed and work. How should international sharing work? How design an ethical informed consent?

An underlying critique: the regulatory systems are becoming increasingly complex and opaque. The international community is building systems that should respond to that. According to the authors in fact, it is time to turn the ship around. Biobank researchers have a moral responsibility to look at and assess their work in relation to the bigger picture: the shared norms and values of current society. Research ethics shouldn’t only be a matter of bioethicists writing guidelines that professionals have to follow. Ethics should be practiced through discourse and regulatory frameworks need to be part of that public discourse. Ethics review should be then not merely application of bureaucracy and a burden for researchers but an arena where researchers discuss their projects, receive advice and practice their ethics skills.

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