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Governing Biobanks: Understanding the Interplay between Law and Practice

Jane Kaye, Susan M C Gibbons, Catherine Heeney, Michael Parker, Andrew Smart

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Biobanks are proliferating rapidly worldwide because they are powerful tools and organizational structures for undertaking medical research. By linking samples to data on the health of individuals, it is anticipated that biobanks will be used to explore the relationship between genes, environment, and lifestyle for many diseases, as well as the potential of individually-tailored drug treatments based on genetic predisposition. However, they also raise considerable challenges for existing legal frameworks and research governance structures. This clear and comprehensive book critically examines the current governance structures in place for biobanks in England and Wales. It shows that the technologies, techniques, and practices involved in biobanking do not always conform neatly to the existing legal principles and frameworks that apply to other areas of medical research. Using a socio-legal approach, including interview data gathered from the scientific community, the book provides unique insights and makes recommendations about appropriate governance mechanisms for biobanking in the future. It also explores the issues around the secondary use of information, such as consent and how to protect privacy, when biobanks are accessed by a number of different third parties. These issues have relevance both within England and Wales and to a wide international audience, as well as for other areas where large datasets are used.

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