

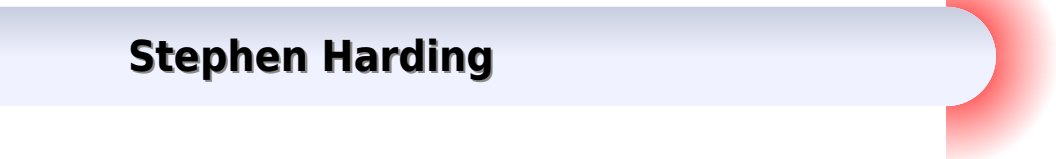
Biobanks

Governance in comparative
perspective

Edited by
Herbert Gottweis and
Alan Petersen

Biobanks Governance In Comparative Perspective

Stephen Harding



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Biobanks Herbert Gottweis, Alan Petersen, 2008-04-28 This groundbreaking book makes it clear that biobanks are a phenomenon that cannot be disconnected from considerations of power politics and the reshaping of current practices in governance

Principles and Practice in Biobank Governance Mark Stranger, 2016-04-15 Rapid technological advances the establishment of large scale biobanks and the exchange of data across international boundaries raise a variety of questions for regulators struggling with the problem of how to govern such stores of information and the processes connected with them Engaging with the pressing issues of privacy consent access to data and benefit sharing Principles and Practice in Biobank Governance draws together the latest empirical research from the UK Europe America Australia and Asia to focus on these challenges Current models of governance are critiqued principles and policies are debated and new models and theoretical frameworks are presented through this intellectually stimulating informative volume This truly international volume offers new insights from a range of disciplinary perspectives and will be essential reading for policy makers and scholars across a range of social sciences including sociology bioethics law and social policy

Ethics, Law and Governance of Biobanking Deborah Mascalzoni, 2015-01-22 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

The Handbook of Genetics & Society Paul Atkinson, Peter Glasner, Margaret Lock, 2009-07-02 An authoritative Handbook which offers a discussion of the social political ethical and economic consequences and implications of the new bio sciences The Handbook takes an interdisciplinary approach providing a synoptic overview of contemporary international social science research on genetics genomics and the new life

sciences It brings together leading scholars with expertise across a wide ranging spectrum of research fields related to the production use commercialisation and regulation of genetics knowledge The Handbook is structured into seven cross cutting themes in contemporary social science research on genetics with introductions written by internationally renowned section editors who take an interdisciplinary approach to offer fresh insights on recent developments and issues in often controversial fields of study The Handbook explores local and global issues and critically approaches a wide range of public and policy questions providing an invaluable reference source to a wide variety of researchers academics and policy makers

Trust in Biobanking Peter Dabrock,Jochen Taupitz,Jens Ried,2012-02-22 Biobanks are promising instruments of biomedical research and of transnational medicine in particular Ethical legal and social issues associated with biobanking however have recently led to a more critical view on this concept All efforts addressing these concerns have been grounded on well established standards of biomedical ethics such as informed consent procedures protection of individual autonomy benefit sharing etc By additionally highlighting the widely neglected aspect of trust this book aims at broadening the horizon of the ELSI debate and thus filling a gap in current research on biobanking The contributions of leading experts and junior researchers cover a wide field of disciplines relevant for biobanking including law ethics medicine public health social sciences philosophy and theology

Biobanks and Tissue Research Christian Lenk,Judit Sándor,Bert Gordijn,2011-07-30 The research field of biobanks and tissue research is highly promising Many projects around the globe are involved in the collection of human tissue and health data for research purposes These initiatives are driven by the perspective of decisive breakthroughs in the knowledge of the genetic pathways involved in widespread diseases However there are considerable ethical and legal challenges to be considered as well These challenges encompass the use of body material for research purposes the misuse of genetic and other health data by third parties trust in science and medicine concerns regarding privacy use of genetic data for forensic applications by the state and the police and regulatory issues This volume is divided into three parts the inclusion of the public the rights of donors and patients examples and recommendations for the future of tissue research It presents a comprehensive overview of the most important topics in the field by renowned scholars in medical ethics and biolaw

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production to account for the kinship that has emerged in both informal and commercial modes of innovation and foregrounds the value of use as crucial to the articulation of intellectual property within contemporary models of production and commercialization in the digital

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The Politics of Bioethics Alan Petersen, 2011-01-25
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