Biobanks

Governance in comparative perspective

Edited by Herbert Gottweis and Alan Petersen

Biobanks Governance In Comparative Perspective

Johanna Gibson

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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 **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 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 The Logic of Innovation Johanna Gibson, 2016-03-03 The Logic of Innovation examines not merely the supposed problem of the efficacy and relevance of intellectual property and the nature of innovation and creativity in a digital environment but also the very circumstances of that inquiry itself Social life has itself become a sphere of production but how might that be understood within the cultural and structural transformation of creativity innovation and property Through a highly original interlocutory and therapeutic approach to the issues in play the author addresses the concepts of innovation and the digital by means of an investigation through literature and the imagination of new scenarios for language business and legal reform The book undertakes a complex inquiry into innovation and property through the wonder of Alice's journeys in Wonderland and through the Looking glass The author presents a new theory of familiar 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 Biotechnology & Genetic Engineering Reviews Stephen Harding, 2009-04-01 Containing more than a dozen original major review articles from authors published in leading journals and covering important developments in industrial agricultural and medical applications of biotechnology this newest edition from the well established hardcover review series focuses primarily on the genetic manipulation of organisms Covering issues ranging from gene expression and genetic regulations to plant bioreactors and enzymatic processing this reference will benefit students in the fields of biochemistry genetics molecular biology and pharmaceutical sciences 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

Global Perspectives on Precision Medicine Evangel Sarwar, 2023-04-04 This book presents the promises of Precision Medicine PM and the challenges of its implementation in daily clinical routine while addressing the anticipated ethical and social implications It is the first book that critically analyzes the potential and the dilemmas relevant to genomics and precision medicine from healthcare public health and global perspectives. The nine chapters presented in this book elaborate on pharmacogenomics crucial role in maximizing the potential benefits and minimizing medication s potential risks in groups of people especially in cancer treatment and other health conditions Infectious and non communicable diseases NCDs are also discussed in this book by identifying challenges and ways to overcome them Essential concepts are addressed such as health related benefits and harm to individuals and the broader community including threats to individual privacy and autonomy which warrant just distribution of scarce resources The book also identifies and addresses the lack of competency in the healthcare workforce in the era of PM and discusses the path to laying the ethical foundation for the implementation of PM in healthcare organizations Research Handbook on Information Policy Duff, Alistair S., 2021-10-12 This comprehensive and innovative Research Handbook tackles the pressing issues confronting us at the dawn of the global network society including freedom of speech government transparency and the digital divide Engaging with controversial problems of public policy including freedom of expression copyright and information inequality the Research Handbook on Information Policy offers a well rounded exploration of the history and future of this vital field

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