



# Genetic Secrets:

Protecting Privacy  
and Confidentiality in  
the Genetic Era

edited by Mark A. Rothstein

# Genetic Secrets Protecting Privacy Confidentiality In The Genetic Era

**Robert R. Redfield**



## **Genetic Secrets Protecting Privacy Confidentiality In The Genetic Era:**

*Genetic Secrets* Mark A. Rothstein, 1997-01-01 The dramatic explosion of information brought about by recent advances in genetic research brings welcome scientific knowledge Yet this new knowledge also raises complex and troubling issues concerning privacy and confidentiality This thought provoking book is the first comprehensive exploration of these ethical legal and social issues Distinguished experts in law medicine bioethics public health science policy clinical genetics philosophy and other fields consider the many contexts in which issues of genetic privacy arise from research and clinical settings to workplaces insurance offices schools and the courts The first chapters of this book set out a framework for analyzing genetic privacy and confidentiality comparing genetic privacy with other forms of medical privacy Later chapters deal with such topics as concerns that arise in the health care setting the patient physician relationship genetic counseling and privacy the effect of new technology the role of commercial genomics forensic DNA applications nonmedical uses of genetic information the law of medical and genetic privacy in the workplace implications of genetic testing for health and life insurance and a review of ethics and law in the United States and abroad In the concluding chapter Mark A Rothstein discusses flaws in existing and proposed legislation designed to protect genetic privacy and confidentiality and he offers a new set of guidelines for policy makers

Genetic Discrimination and Genetic Privacy in a Comparative Perspective Janneke H. Gerards, A. W. Heringa, Heleen L. Janssen, 2005 During the last decades a better understanding of the influence of genetic factors on the onset of illness and disease has evolved Unfortunately however the information revealed by genetic tests is not always accurate and reliable and its probabilistic value is often limited Throughout the world the possibility of genetic testing and the availability of individual genetic information have therefore caused increasing social concern especially since many actors outside the medical profession such as health and life insurance companies and employers have shown a growing interest in individual genetic information In many states as well as on the international level there is an ongoing debate about the balance that should be struck between the protection of the individual against misuse of genetic information and the interests of social actors and genetic research institutes and about the policy options that are at hand to reduce the risks that are created by the availability of genetic information This book offers some clarity as to the choices that have been made in various legal systems both national and international with respect to the regulation of genetic information On the basis of an elaborate analysis of relevant legislation policy approaches and case law in the United States the various European states and on the international level the book aims to provide insight in the issues that must be deemed relevant in considering and eventually introducing regulative measures with respect to genetic information

**Brief van Christiaan Pieter Raven (1906-) aan A.A. Pulle Utrecht**, 1946

*Genetic Privacy: An Evaluation Of The Ethical And Legal Landscape* Terry Sheung-hung Kaan, Calvin Wai-loon Ho, 2013-07-04 Privacy is an unwieldy concept that has eluded an essentialised definition despite its centrality and importance in the body of bioethics The compilation presented in this volume represents continuing

discussions on the theme of privacy in the context of genetic information. It is intended to present a wide range of expert opinion in which the notion of privacy is examined from many perspectives in different contexts and imperatives and in different societies with the hope of advancing an understanding of privacy through the examination and critique of some of its evolving component concepts such as notions of what constitute the personal, the context of privacy, the significance and impact of the relational interests of others who may share the same genetic inheritance and mechanisms for the protection of privacy as well as of their limitations among others. More specifically, the discussions in this volume encourage us to think broadly about privacy as encompassing values that are entailed in the sociality of context and of relations and also as freedom from illegitimate and excessive surveillance. A long-standing question that continues to challenge us is whether genetic information should be regarded as exceptional as it is often perceived. A conclusion that could be derived from this volume is that while genetic information may be significant, it is not exceptionally so. The work presented in this volume underlines the continuing and growing relevance of notions of privacy to genomic science and the need to take ownership of a genetic privacy for the future through broad, rigorous and open discussion.

Contributors: Alastair V Campbell, Benjamin Capps, Jacqueline JL Chin, Oi Lian Kon, Kenji Matsui, Thomas H Murray, Nazirudin Mohd Nasir, Dianne Nicol, Anh Tuan Nuyen, Onora O'Neill, Margaret Otowski, Yvette van der Eijk, Chunshui Wang, Ross S White.

Research Involving Human Biological Materials United States. National Bioethics Advisory Commission, 1999

Research Involving Human Biological Materials: Commissioned papers United States. National Bioethics Advisory Commission, 1999

**Research Involving Human Biological Materials: Commissioned papers. Privacy and the analysis of stored tissues** United States. National Bioethics Advisory Commission, 1999

Distributive Justice and the New Medicine George Patrick Smith, 2010-01-01

Smith has packed an incredible amount of information into this relatively short and clearly written book. His erudition is unquestionable and his knowledge of current trends in medical technology and the ethical issues surrounding them is obvious on every page. P Jenkins Choice. George P Smith is one of the world's leading experts on the legal and ethical issues raised by modern medicine. His book is a wide-ranging and deeply informed and considered analysis of those issues with particular emphasis on the inequality with which the benefits of modern medicine are bestowed on the sick. Knowledgeable as well about the technical aspects of the biomedical revolution, Smith writes with insight and authority and offers a perspective that will influence the policy debates. Richard A Posner, United States Court of Appeals for the Seventh Circuit and University of Chicago Law School, US. While much has been written about the various issues addressed in this book—genetics, cloning, informed consent, organ donation—Smith's book moves beyond traditional legal analysis, tying these issues together by examining them through the lens of distributive justice. He thus provides the reader with a unique and valuable perspective on this important area. *Distributive Justice and the New Medicine* will be of interest to all those interested in health law and bioethics and in particular for those interested in distributive justice. Belinda Bennett, *Journal of Law Social*

Justice and Global Development Professor George P Smith's *Distributive Justice and the New Medicine* is a major new work by one of the world's leading medical lawyers. This book brings important new insights into the complex area of rationing health care resources and should be read by anyone interested in seeking to create a just society. Jonathan Herring, Exeter College, University of Oxford, UK. Is the advancement of scientific knowledge and the development of biomedical technologies known as the New Medicine desirable? George P Smith asks this fundamental question while also confronting the distribution of these scarce medical resources. Law, economics, medical science, philosophy and ethics all coalesce in this discussion of how to structure normative standards of conduct that will improve the quality of human life. The author begins by examining various economic constructs as aids for achieving a fair and equitable delivery of health care services. He then assesses their level of practical application and evaluates the costs and benefits to society of pursuing the development and use of the New Medicine. The book ends with a case study of organ and tissue transplantation that illustrates the implementation of distributive justice. The author concludes that as long as clinical medicine maintains its focus on healing and alleviating suffering among patients, a point of equilibrium will be reached that advances the common good. This timely and compelling exploration will be a must read for scholars, researchers, policymakers and all those interested in advances in medical technology and the issues surrounding access to health care.

#### **Genetics, Disability and the Law** Aisling de

Paor, 2017-09-21. While advances in science and technology bring many advantages, we must not ignore the harm that they can cause. Rapid changes in genetic testing are a prime example, and indicators can now help to detect, address and treat diseases. However, in this new study, Aisling de Paor examines how genetic testing is also being used for non-medical reasons, for example, for work opportunities and insurance coverage. *Genetics, Disability and the Law* is the first book of its kind to substantively consider an EU level response to the use of genetic information. de Paor discusses how to help genetic and scientific research to evolve and grow, how to enhance public confidence in research and how to control it so that it recognises our values and fundamental human rights. An understudied but vitally important topic, de Paor's work provides a valuable and timely contribution to the field of disability rights.

#### *Research Involving Human Biological Materials:*

*Commissioned papers. Privacy and the analysis of stored tissues*, 1999. **Genetic Discrimination** Gerard Quinn, Aisling de

Paor, Peter Blanck, 2014-11-20. As genetic technologies advance, genetic testing may well offer the prospect of detecting the onset of future disabilities. Some research also forwards that certain behavioural profiles may have a strong genetic basis, such as the determination to succeed or the propensity for risk-taking. As this technology becomes more prevalent, there is a danger that genetic information may be misused by third parties and that particular genetic profiles may be discriminated against by employers, by providers of social goods and services such as insurance companies, and even by educational facilities. This book explores the different forms and potential uses of genetic testing. Drawing together leading experts in disability law, bioethics, health law and a range of related fields, it highlights the ethical and legal challenges arising as a

result of emerging and rapidly advancing genetic science On examining transatlantic perspectives on the matter chapters in the book ask whether the US Genetic Information Nondiscrimination Act GINA is proving to be an effective tool in addressing the issue of genetic discrimination and alleviating fears of discrimination The book also reviews what insights may be gained from GINA within employment and health insurance contexts and asks how the UN Convention on the Rights of Persons with Disabilities CRPD may impact similar debates within the European Union The book focuses particularly on the legislative and policy framework in the European Union with an emphasis on the gaps in protection and the scope for specific legislative action in this area This book will be of great interest to scholars and students of discrimination law bioethics and disability law and will be of considerable use to legal practitioners medical practitioners and policy makers in this area Genetic Justice Sheldon Krinsky, Tania Simoncelli, 2012 Two leading authors on medical ethics science policy and civil liberties take a hard look at how the United States has balanced the use of DNA technology particularly the use of DNA databanks in criminal justice with the privacy rights of its citizenry The authors explore many controversial topics including the legal precedent for taking DNA from juveniles the search for possible family members of suspects in DNA databases the launch of DNA dragnets among local populations and the warrantless acquisition by police of so called abandoned DNA in the search for suspects Most intriguing they explode the myth that DNA profiling is infallible which has profound implications for criminal justice **Routledge Handbook of Medical Law and Ethics** Yann Joly, Bartha Maria Knoppers, 2014-09-19 This book explores the scope application and role of medical law regulatory norms and ethics and addresses key challenges introduced by contemporary advances in biomedical research and healthcare While mindful of national developments the handbook supports a global perspective in its approach to medical law Contributors include leading scholars in both medical law and ethics who have developed specially commissioned pieces in order to present a critical overview and analysis of the current state of medical law and ethics Each chapter offers comprehensive coverage of longstanding and traditional topics in medical law and ethics and provides dynamic insights into contemporary and emerging issues in this heavily debated field Topics covered include Bioethics health and human rights Medical liability Law and emerging health technologies Public health law Personalized medicine The law and ethics of access to medicines in developing countries Medical research in the genome era Emerging legal and ethical issues in reproductive technologies This advanced level reference work will prove invaluable to legal practitioners scholars students and researchers in the disciplines of law medicine genetics dentistry theology and medical ethics *Cyber Law, Privacy, and Security: Concepts, Methodologies, Tools, and Applications* Management Association, Information Resources, 2019-06-07 The internet is established in most households worldwide and used for entertainment purposes shopping social networking business activities banking telemedicine and more As more individuals and businesses use this essential tool to connect with each other and consumers more private data is exposed to criminals ready to exploit it for their gain Thus it is essential to continue discussions involving policies that regulate and

monitor these activities and anticipate new laws that should be implemented in order to protect users Cyber Law Privacy and Security Concepts Methodologies Tools and Applications examines current internet and data protection laws and their impact on user experience and cybercrime and explores the need for further policies that protect user identities data and privacy It also offers the latest methodologies and applications in the areas of digital security and threats Highlighting a range of topics such as online privacy and security hacking and online threat protection this multi volume book is ideally designed for IT specialists administrators policymakers researchers academicians and upper level students

**Security and Privacy** Joseph Savirimuthu, 2016-12-05 During the last decade in particular the levels of critical engagement with the challenges posed for privacy by the new technologies have been on the rise Many scholars have continued to explore the big themes in a manner which typifies the complex interplay between privacy identity security and surveillance This level of engagement is both welcome and timely particularly in a climate of growing public mistrust of State surveillance activities and business predisposition to monetize information relating to the online activities of users This volume is informed by the range of discussions currently conducted at scholarly and policy levels The essays illustrate the value of viewing privacy concerns not only in terms of the means by which information is communicated but also in terms of the political processes that are inevitably engaged and the institutional regulatory and cultural contexts within which meanings regarding identity and security are constituted

*The Ethics of Biomedical Big Data* Brent Daniel Mittelstadt, Luciano Floridi, 2016-08-03 This book presents cutting edge research on the new ethical challenges posed by biomedical Big Data technologies and practices Biomedical Big Data refers to the analysis of aggregated very large datasets to improve medical knowledge and clinical care The book describes the ethical problems posed by aggregation of biomedical datasets and re use re purposing of data in areas such as privacy consent professionalism power relationships and ethical governance of Big Data platforms Approaches and methods are discussed that can be used to address these problems to achieve the appropriate balance between the social goods of biomedical Big Data research and the safety and privacy of individuals Seventeen original contributions analyse the ethical social and related policy implications of the analysis and curation of biomedical Big Data written by leading experts in the areas of biomedical research medical and technology ethics privacy governance and data protection The book advances our understanding of the ethical conundrums posed by biomedical Big Data and shows how practitioners and policy makers can address these issues going forward

Governing Biobanks Jane Kaye, Susan Gibbons, Catherine Heeney, Andrew Smart, 2012-02-03 Biobanks are proliferating rapidly worldwide because they are powerful tools and organisational 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 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 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 this 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 Buying your Self on the Internet

Phillips Andelka M. Phillips,2019-07-17 This book examines the rise of the direct to consumer genetic testing industry DTC and its use of wrap contracts It uses the example of DTC to show the challenges that disruptive technologies pose for societies and for regulation It also uses the wrap contracts of DTC companies to explore broader issues with online contracting **An Introduction to Human Molecular Genetics** Jack J. Pasternak,2005-06-03 An Introduction to Human Molecular Genetics Second Edition Jack J Pasternak The Second Edition of this internationally acclaimed text expands its coverage of the molecular genetics of inherited human diseases with the latest research findings and discoveries Using a unique systems based approach the text offers readers a thorough explanation of the gene discovery process and how defective genes are linked to inherited disease states in major organ and tissue systems All the latest developments in functional genomics proteomics and microarray technology have been thoroughly incorporated into the text The first part of the text introduces readers to the fundamentals of cytogenetics and Mendelian genetics Next techniques and strategies for gene manipulation mapping and isolation are examined Readers will particularly appreciate the text s exceptionally thorough and clear explanation of genetic mapping The final part features unique coverage of the molecular genetics of distinct biological systems covering muscle neurological eye cancer and mitochondrial disorders Throughout the text helpful figures and diagrams illustrate and clarify complex material Readers familiar with the first edition will recognize the text s same lucid and engaging style and will find a wealth of new and expanded material that brings them fully up to date with a current understanding of the field including New chapters on complex genetic disorders genomic imprinting and human population genetics Expanded and fully revised section on clinical genetics covering diagnostic testing molecular screening and various treatments This text is targeted at upper level undergraduate students graduate students and medical students It is also an excellent reference for researchers and physicians who need a clinically relevant reference for the molecular genetics of inherited human diseases **Human Population Genetic Research in Developing Countries** Yue Wang,2013-11-12 Human population genetic research HPGR seeks to identify the diversity and variation of the human genome and how human group and individual genetic diversity has developed This book asks whether developing countries are well prepared for the ethical and legal conduct of human population genetic research with specific regard to vulnerable target group protection



The book highlights particular issues raised by genetic research on populations as a whole such as the potential harm specific groups may suffer in genetic research and the capacity for current frameworks of Western developed countries to provide adequate protections for these target populations Using The People s Republic of China as a key example Yue Wang argues that since the target groups of HPGR are almost always from isolated and rural areas of developing countries the ethical and legal frameworks for human subject protection need to be reconsidered in order to eliminate or at least reduce the vulnerability of those groups While most discussion in this field focuses on the impact of genetic research on individuals this book breaks new ground in exploring how the interests of target groups are also seriously implicated in genetic work In evaluating current regulations concerning prevention of harm to vulnerable groups the book also puts forward an alternative model for group protection in the context of human population genetic research in developing countries The book will be of great interest to students and academics of medical law ethics and the implications of genetic research

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