

Populations and Genetics

Legal and Socio-Ethical Perspectives

Edited by

Bartha Maria Knoppers



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Populations And Genetics Legal And Socioethical:

Populations and Genetics Bartha Maria Knoppers, 2003-01-01 Thirty five papers from the third International DNA Sampling Conference held in Montreal in September 2002 provide a critical discussion of the socio ethical and legal issues surrounding DNA sampling in communities and populations around the globe Contributors address topics related to biobanks and databases community engagement confidentiality *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 **The Ethics and Governance of Human Genetic Databases** Matti Häyry, Ruth Chadwick, Vilhjálmur Árnason, Gardar Árnason, 2007-04-19 The Medical Biobank of Umeå in Sweden deCODE's Health Sector Database in Iceland the Estonian Genome Project and the UK Biobank contain health data and genetic data from large populations Some include genealogical or lifestyle information They are resources for research in human genetics and medicine exploring interaction between genes lifestyle environmental factors and health and diseases The collection storage and use of this data raise ethical legal and social issues In this book first published in 2007 bioethics scholars examine whether existing ethical frameworks and social policies reflect people's concerns and how they may need to change in light of new scientific and technological developments The ethical issues of social justice genetic discrimination informational privacy trust in science and consent to participation in database research are analyzed whilst an empirical survey conducted in the four countries demonstrates public views of privacy and related moral values in the context of human genetic databases *Ethics and Law of Intellectual Property* Christian Lenk, Nils Hoppe, 2016-05-13 Divided into three parts this edited volume gives an overview of current topics in law and ethics in relation to intellectual property It addresses practical issues encountered in everyday situations in politics research and innovation as well as some of the underlying theoretical concepts In addition it provides an insight into the process of international policy making showing the current problems in the area of intellectual property in science and research It also highlights changes in the

fundamental understanding of common and private property and the possible implications and challenges for society and politics

Creation and Governance of Human Genetic Research Databases OECD, 2006-10-25 Summarises proceedings of a conference looking at examples of human genetic research databases how they are established how they are managed and governed how they might be commercialised and what the policy considerations might be

The Oxford Textbook of Clinical Research Ethics Ezekiel J. Emanuel, Christine C. Grady, Robert A. Crouch, Reidar K. Lie, Franklin G. Miller, David D. Wendler, 2011-02 The Oxford Textbook of Clinical Research Ethics is the first comprehensive and systematic reference on clinical research ethics Under the editorship of experts from the U S National Institutes of Health of the United States the book s 73 chapters offer a wide ranging and systematic examination of all aspects of research with human beings Considering the historical triumphs of research as well as its tragedies the textbook provides a framework for analyzing the ethical aspects of research studies with human beings Through both conceptual analysis and systematic reviews of empirical data the contributors examine issues ranging from scientific validity fair subject selection risk benefit ratio independent review and informed consent to focused consideration of international research ethics conflicts of interests and other aspects of responsible conduct of research The editors of The Oxford Textbook of Clinical Research Ethics offer a work that critically assesses and advances scholarship in the field of human subjects research Comprehensive in scope and depth this book will be a crucial resource for researchers in the medical sciences as well as teachers and students

Frameworks of Choice Margaret Sleeboom-Faulkner, 2010 Frameworks of Choice verkent de culturele en politieke aspecten van voorspellende en genetische tests Het boek analyseert de sociale culturele en economische gevolgen voor het individu na een voorspellende of genetische screening Margaret Sleeboom Fau

Essays on Biomedical Law and Ethics Brigitte E.S. Jansen, 2017-10-10 The Book The collection of five given papers and presentations from conferences between 2005 and 2008 are discussion papers The perspectives of the essays are based on biomedical ethics and legal reflections The papers were presented on important international conferences and congresses Included are the following talks Biotechnology and Economy An ethical conflict of interest Human Biobanks Trustees and aspects of the current German discussion Biobanking and genetic testing A comparison between European countries and India New Epidemics A chance for Social rights Justice and Health and Genetic testing pharmacogenetics privacy and the responsibility of doctors in clinical trials The author hopes that this collection will stimulate further discussion

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

Community Genetics and Genetic Alliances Aviad E. Raz,2009-09-10 The social and bioethical aspects of carrier testing and its assimilation by specific groups are examined through several qualitative case studies in traditional religious ethnic as well as modern secular consumerist communities in Israel and the U S Comparing the views of community members and health professionals the analysis offers a new look on the relations between eugenics and genetic responsibility

Genetic Testing Neil F. Sharpe,Ronald F. Carter,2006-01-03 A complete review of the issues with specific recommendations and guidelines With over 1 000 tests commercially available genetic testing is revolutionizing medicine Health care professionals diagnosing and treating patients today must consider genetic factors the risks and limitations of genetic testing and the relevant law Genetic Testing Care Consent and Liability offers the only complete practical treatment of the genetic clinical ethical and legal issue surrounding genetic testing The authors present protocols policies and models of care that are currently in use and explain the legal framework for genetic testing and counseling that has developed in North America particularly with regard to the law of medical malpractice This essential book features an international roster of esteemed contributors including Nancy P Callanan Bonnie S LeRoy Carole H Browner H Mabel Preloran Riyana Babul Hirji Cheryl Shuman M J Esplen Maren T Scheuner Dena S Davis JonBeckwith Lisa Geller Mark A Hall Andrew R MacRae David Chitayat Roxanne Mykitiuk Stephanie Turnham Mireille Lacroix Jinger G Hoop Edwin H Cook Jr S H Dinwiddie Elliot S Gershon C Anthony Rupar Lynn Holt Bruce R Korf Anne Summers S Annie Adams Daniel L Van Dyke Rhett P Ketterling Erik C Thorland Timothy Caulfield Lorraine Sheremeta Richard Gold Jon F Merz David Castle Peter J Bridge JS Parboosingh Patricia T Kelly Julianne M O Daniel Allyn McConkie Rosell Beatrice Godard Bartha Maria Knoppers David Weisbrot The coverage also includes Genetic screening including prenatal neonatal carrier and susceptibility testing Diagnosis risk assessment confidentiality and clinical legal issues related to follow up Interpreting test results and communicating them to patients psychological considerations Informed consent Family history evaluations Referral to medical geneticists and genetic counselors Genetic Testing Care Consent and Liability is a must have resource for clinical geneticists genetic counselors specialists family physicians nurses public health professionals and medical students Human Genetic Biobanks in Asia Margaret Sleeboom-Faulkner,2008-11-19 This volume investigates human genetic biobanking and its regulation in various Asian countries and areas including Japan Mainland China Taiwan Hong Kong India and Indonesia It sheds light on how cultural socio political and economic factors influence the set up of bioethical regulation for human genetic biobanks and how bioethical sensitivities surrounding biobanks are handled Apart from placing discourses of trust in an international perspective the comparative materials presented in this volume also put into perspective the concepts of

genetic theft and exploitation and genetic wealth and trust This collection contains case studies of biobanking practices in societies with different needs and welfare levels and provides insights into government strategies towards genetic resources by examining bioethics as practised at home

Ethical Issues in Governing Biobanks Nikola Biller-Andorno, Alexander M. Capron, 2016-05-13 Population genomics research drawing on genetic databases has expanded rapidly with some of this information being combined in biobanks Managing this information in an appropriate way is a highly complex ethical issue in the health policy arena This book combines theoretical and empirical research to analyze the areas of conflict and consensus in the regulatory and ethical frameworks that have been developed to govern biobanks Ethicists from the Department of Ethics Trade Human Rights and Health Law ETH of the World Health Organization the Institute of Biomedical Ethics of Geneva University and the Institute of Biomedical Ethics of the University of Zurich with the support of the Geneva International Academic Network GIAN examine the conditions under which genetic databases can be established kept and made use of in an ethically acceptable way In addition to a comprehensive review of the scientific literature and a comparative analysis of existing normative frameworks they present the results of in depth interviews with experts around the world concerning the most unresolved and controversial issues The results of that study combined with their normative analysis leads to recommendations for a better international framework

Accessing and Sharing the Benefits of the Genomics Revolution Peter W.B. Phillips, Chika B. Onwuekwe, 2007-05-09 There is a veritable gold rush mentality in the life science world as scientists entrepreneurs and multinationals are staking claims to the code of life embodied in the world s current stock of plants animals microbes and human populations This edited volume explores the legal economic and political context for the debate about intellectual property rights for traditional knowledge and genetic resources and critically analyses the theory and practice of access and benefits sharing efforts around the world The book also investigates the current flashpoints the David and Goliath battle between Monsanto and Percy Schmeiser over farmers rights the dispute over coexistence of GM and organic production and the ownership and control of human genetic materials stored in human gene banks around the world

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

Ethical Issues of Human Genetic Databases Bernice Elger, 2016-05-13 Following the boom in population databases in recent years there has been sustained and intense

international debate about political processes and legal and ethical issues surrounding the protection and use of genetic data. As a result, several national and international organizations and committees have published widely differing guidelines and statements concerning genetic databases and biobanks. *Ethical Issues of Human Genetic Databases* compares the new area of biobanking with the tradition of ethically accepted classical research and highlights the distinctive features of existing databases and guidelines. The volume identifies areas of consensus and controversy while investigating the challenges posed to classical health research ethics by the existence of genetic databases, analyzing the reasons for such varying guidelines. The book will be essential to academics, biobankers, policy makers, and researchers in the field of medical ethics. **Genetic**

Databases Oonagh Corrigan, Richard Tutton, 2004-07-31 *Genetic Databases* offers a timely analysis of the underlying tensions, contradictions, and limitations of the current regulatory frameworks for and policy debates about genetic databases. Drawing on original empirical research and theoretical debates in the fields of sociology, anthropology, and legal studies, the contributors to this book challenge the prevailing orthodoxy of informed consent and explore the relationship between personal privacy and the public good. They also consider the multiple meanings attached to human tissue and the role of public consultations and commercial involvement in the creation and use of genetic databases. The authors argue that policy and regulatory frameworks produce a representation of participation that is often at odds with the experiences and understandings of those taking part. The findings present a serious challenge for public policy to provide mechanisms to safeguard the welfare of individuals participating in genetic databases. *Just Genes* Carol Isaacson Barash, 2007-12-30 Advances in genetics research, largely though not entirely spawned by the Human Genome Project, have led to a broad array of new technologies that promise to revolutionize life as we have known it. Medicine and agriculture are already starting to utilize new technologies to greatly improve disease prevention and treatment and food production. Yet these improvements often raise ethical questions that are not easy to untangle. Some have gone as far as to argue that certain applications, such as embryonic stem cell research, threaten the very fiber of our moral compass. While the application of scientific advances to better humankind has always raised thorny ethical issues, the ethical impact of genetic advances arguably reaches a new height because the applicability of advances is exceptionally broad, deep, and potentially irreversible. To utilize such technologies could mean saving thousands of lives, but where and how do we draw the line? Here Barash sheds light on the actual ethical concerns surrounding various types of genetic technologies, introducing readers to the competing issues at stake in the arguments about the scientific application of the new technologies available and those on the horizon. She begins by illustrating the history of genetic advances, their societal applications, and the ethical issues that have arisen from those applications. Using case studies and examples throughout, she walks readers through the various considerations involved in a variety of areas related to the application of genetic technologies currently available and possible in the future. Covering topics ranging from stem cell research to genetically modified food, genetic mapping to cloning, this book offers a thoughtful

approach to the complex issues at play in the various fields of genetic technologies The Oxford Handbook of Bioethics
Bonnie Steinbock, 2007-02-16 Bonnie Steinbock presents The Oxford Handbook of Bioethics an authoritative state of the art guide to current issues in bioethics Thirty four contributors reflect the interdisciplinarity that is characteristic of bioethics and its increasingly international character Thirty topics are covered in original essays written by some of the world's leading figures in the field as well as by some newer up and comers The essays address both perennial issues such as the methodology of bioethics autonomy justice death and moral status and newer issues such as biobanking stem cell research cloning pharmacogenomics and bioterrorism Other topics concern mental illness and moral agency the rule of double effect justice and the elderly the definition of death organ transplantation feminist approaches to commodification of the body life extension advance directives physician assisted death abortion genetic research population screening enhancement research ethics and the implications of public and global health for bioethics Anyone who wants to know how the central debates in bioethics have developed in recent years and where the debates are going will want to consult this book It will be an invaluable resource not only for scholars and graduate students in bioethics but also for those in philosophy medicine law theology social science public policy and public health who wish to keep abreast of developments in bioethics **Genetic Dissection of Complex Traits** D.C. Rao, C. Charles Gu, 2008-04-23 The field of genetics is rapidly evolving and new medical breakthroughs are occurring as a result of advances in knowledge of genetics This series continually publishes important reviews of the broadest interest to geneticists and their colleagues in affiliated disciplines Five sections on the latest advances in complex traits Methods for testing with ethical legal and social implications Hot topics include discussions on systems biology approach to drug discovery using comparative genomics for detecting human disease genes computationally intensive challenges and more

Reviewing **Populations And Genetics Legal And Socioethical**: Unlocking the Spellbinding Force of Linguistics

In a fast-paced world fueled by information and interconnectivity, the spellbinding force of linguistics has acquired newfound prominence. Its capacity to evoke emotions, stimulate contemplation, and stimulate metamorphosis is actually astonishing. Within the pages of "**Populations And Genetics Legal And Socioethical**," an enthralling opus penned by a very acclaimed wordsmith, readers embark on an immersive expedition to unravel the intricate significance of language and its indelible imprint on our lives. Throughout this assessment, we shall delve in to the book is central motifs, appraise its distinctive narrative style, and gauge its overarching influence on the minds of its readers.

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