



Evaluating Human Genetic Diversity

NATIONAL RESEARCH COUNCIL

Evaluating Human Genetic Diversity

Bernard Lo



Evaluating Human Genetic Diversity:

Evaluating Human Genetic Diversity National Research Council, Division on Earth and Life Studies, Commission on Life Sciences, Committee on Human Genome Diversity, 1998-02-19 This book assesses the scientific value and merit of research on human genetic differences including a collection of DNA samples that represents the whole of human genetic diversity and the ethical organizational and policy issues surrounding such research Evaluating Human Genetic Diversity discusses the potential uses of such collection such as providing insight into human evolution and origins and serving as a springboard for important medical research It also addresses issues of confidentiality and individual privacy for participants in genetic diversity research studies

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Commodifying Bodies Nancy Scheper-Hughes, Loic Wacquant, 2002-10-10 Increasingly the body is a possession that does not belong to us It is bought and sold bartered and stolen marketed wholesale or in parts The professions especially reproductive medicine transplant surgery and bioethics but also journalism and other cultural specialists have been pliant partners in this accelerating commodification of live and dead human organisms Under the guise of healing or research they have contributed to a new ethic of parts for which the divisible body is severed from the self torn from the social fabric and thrust into commercial transactions as organs secretions reproductive capacities and tissues responding to the dictates of an incipiently global marketplace Breaking with established approaches which prioritize the body as text the chapters in this book examine not only images of the body turned merchandise but actually existing organisms considered at once as material entities semi magical tokens symbolic vectors and founts of lived experience The topics covered range from the cultural disposal and media treatment of corpses the biopolitics of cells sperm banks and eugenics to the international trafficking of kidneys the development of transplant tourism to the idioms of corporeal exploitation among prizefighters as a limiting case of fleshly commodity This insightful and arresting volume combines perspectives from anthropology law medicine and sociology to offer compelling analyses of the concrete ways in which the body is made into a commodity and how its marketization in turn remakes social relations and cultural meanings

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 **Cells and Surveys** National Research Council, Commission on Behavioral and Social Sciences and Education, Committee on Population, 2001-02-19 What can social science and demography in particular reasonably expect to learn from biological information There is increasing pressure for multipurpose household surveys to collect biological data along with the more familiar interviewer respondent information Given that recent technical developments have made it more feasible to collect biological information in non clinical settings those who fund design and analyze survey data need to think through the rationale and potential consequences This is a concern that transcends national boundaries Cells and Surveys addresses issues such as which biologic genetic data should be collected in order to be most useful to a range of social scientists and whether amassing biological data has unintended side effects The book also takes a look at the various ethical and legal concerns that such data collection entails **The Uses of Diversity** Jonathan Kahn, 2025-06-10 Race it is widely understood is a social category that has no genetic basis yet biological notions of race keep reemerging Attempts to redress disparities in biomedical research emphasize recruiting racially representative trial participants Forensic use of DNA evidence purports to pinpoint the race of a potential suspect Genetic ancestry tracing companies explain test results to customers using racial categories The makers of genomic databases seek to ensure racial inclusivity Jonathan Kahn argues that this predicament arises from a surprising source the concept of diversity Ranging across law politics science and medicine he examines the blurring of the distinction between social understandings of race and biological understandings of genetic variation Because diversity has become such a central concept across domains Kahn contends it enables slippage between these contradictory ideas entangling biological and social views of race Tracing the parallel histories of the Human Genome Project workforce diversification efforts U S Supreme Court cases over affirmative action the rise of precision medicine and the COVID 19 vaccine trials among others he shows why diversity is often deployed in ways that threaten to biologize race or undermine efforts to address racial injustice Combining incisive critique and interdisciplinary insight The Uses of Diversity offers bracing new perspective on one of today s most vexed concepts 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 DNA for Archaeologists Elizabeth Matisoo-Smith, K. Ann Horsburgh, 2016-09-16 The ability to use DNA evidence is revolutionizing our understanding

of the past This book introduces archaeologists to the basics of DNA research so they can understand the powers and pitfalls of using DNA data in archaeological analysis and interpretation By concentrating on the principles and applications of DNA specific to archaeology the authors allow archaeologists to collect DNA samples properly and interpret the laboratory results with greater confidence Written by archaeologists who conduct fieldwork as well as laboratory analysis the volume is replete with case examples of DNA work in a variety of archaeological contexts and is an ideal teaching tool for archaeologists and their students

Essentials of Medical Genomics Stuart M. Brown, 2003-07-18 This introductory reference provides a practical concise summary of everything a physician needs to know about genomics and emerging technologies Through extensive illustrative examples this book offers a clear and concise starting point to understanding how medicine has been and will be transformed by genomics and bioinformatics Beginning with a clear overview on the Human Genome Project and its revolutionary impact the book further investigates new technologies in detail including high throughput DNA sequencing genome sequence databases microarrays proteomics pharmacogenomics genetic testing and gene therapy

The Governance of Knowledge Nico Stehr, 2017-07-05 Social surveillance and regulation of knowledge will be one of the most important issues in the near future one that will give rise to unending controversy In *The Governance of Knowledge* Nico Stehr predicts that such concerns will create a new political field namely knowledge policy which will entail regulating dissemination of the anticipated results of rapidly increasing knowledge The number and range of institutionalized standards for monitoring new knowledge has hitherto been relatively small Only in cases of technological applications has social control in the form of political regulation so far intervened All modern societies today have complex regulations and extensive concerns with the registration licensing testing and monitoring of pharmaceutical products The increasingly important and extensive area of intellectual property legislation and administration is an example of social control in which certain measures selectively determine the use of scientific finds and technical knowledge *The Governance of Knowledge* assembles a range of essays that attempt to explore the new field of knowledge politics for the first time It is divided into four parts *The Emergence of Knowledge Politics* *Origins Context and Consequences* *Major Social Institutions and Knowledge Politics* *Case Studies on the Governance of Knowledge and Issues in Knowledge Politics as a New Political Field* Individual chapters concern the emergence of knowledge policy the embeddedness of such regulations in major social institutions and offer case studies of the governance of knowledge and discuss controversial issues that are bound to accompany efforts to regulate new knowledge Professionals and graduate students in the fields of sociology political science social science and law including policymakers and natural scientists will find this book extremely informative

Collaborators Collaborating Monica Konrad, 2012-05-01 As bio capital in the form of medical knowledge skills and investments moves with greater frequency from its origin in First World industrialized settings to resource poor communities with weak or little infrastructure countries with emerging economies are starting to expand new indigenous science bases of their own The case studies here from the

UK West Africa Sri Lanka Papua New Guinea Latin America and elsewhere explore the forms of collaborative knowledge relations in play and the effects of ethics review and legal systems on local communities and also demonstrate how anthropologically informed insights may hope to influence key policy debates Questions of governance in science and technology as well as ethical issues related to bio innovation are increasingly being featured as topics of complex resourcing and international debate and this volume is a much needed resource for interdisciplinary practitioners and specialists in medical anthropology social theory corporate ethics science and technology studies

Population Genomics with R Emmanuel Paradis, 2020-05-05 Population Genomics With R presents a multidisciplinary approach to the analysis of population genomics The methods treated cover a large number of topics from traditional population genetics to large scale genomics with high throughput sequencing data Several dozen R packages are examined and integrated to provide a coherent software environment with a wide range of computational statistical and graphical tools Small examples are used to illustrate the basics and published data are used as case studies Readers are expected to have a basic knowledge of biology genetics and statistical inference methods Graduate students and post doctorate researchers will find resources to analyze their population genetic and genomic data as well as help them design new studies The first four chapters review the basics of population genomics data acquisition and the use of R to store and manipulate genomic data Chapter 5 treats the exploration of genomic data an important issue when analysing large data sets The other five chapters cover linkage disequilibrium population genomic structure geographical structure past demographic events and natural selection These chapters include supervised and unsupervised methods admixture analysis an in depth treatment of multivariate methods and advice on how to handle GIS data The analysis of natural selection a traditional issue in evolutionary biology has known a revival with modern population genomic data All chapters include exercises Supplemental materials are available on line <http://ape package ird.fr/PGR.html>

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 *Why I Am Not a Scientist* Jonathan Marks, 2009-06-23 Highly readable and informative this critical series of vignettes illustrates a long history of the corruption of science by folk beliefs careerism and sociopolitical agendas Marks repeatedly brings home the message that we should challenge scientists especially molecular geneticists before we accept their results and give millions of dollars in public and private funds toward their enterprises Russell Tuttle The University of Chicago Jonathan Marks has produced a personal and compelling story of how science works His involvement in scientific endeavor in human biology and evolution over the past three decades and his keen sense of the workings of science make this book a must read for both scientists and lay readers In this sense the lay reader will learn how scientists should and shouldn't think and some scientists who read this book will come away thinking they are truly not scientists nor would they want to be Rob DeSalle American Museum of Natural History Jonathan Marks's *Why I Am Not a Scientist* provides food for thought and as expected it's digestible In unusually broad perspective this anthropology of knowledge considers science and race and racism gender fraud misconduct and creationism in a way that makes one proud to be called a scientist George J Armelagos Emory University **The Oxford Handbook of Practical Ethics** Hugh LaFollette, 2005-09-15 This is a guide to contemporary thought on ethical issues in all areas of human activity personal medical sexual social political judicial and international from the natural world to the world of business **The Stored Tissue Issue** Robert F. Weir, Robert S. Olick, 2004-05-20 Genetics research with stored human tissues provides many benefits and holds much promise Yet how this critical research is conducted sometimes raises serious ethical legal and social concerns and it is difficult to balance the promise of biomedical research with our time honored commitments to individual choice in such fundamental matters as control over personal health information and the disposition of our bodily tissues Weir and Olick provide a thorough analysis of this critical phase in the era of genomic medicine While strongly supportive of the biomedical research enterprise they develop a critique of many common research practices with banked tissues DNA and genetic data Noting numerous examples of beneficial human tissue research they focus on problematic research practices controversial cases and federal and institutional policies that limit the informed choices of patients and research participants The authors offer a series of recommendations intended to limit the risks of inadequate informed consent to research for individuals families and groups and to strengthen the bonds of trust between the research enterprise and the public upon which biomedical progress depends This book offers a wealth of information plus well reasoned recommendations that will be of keen interest to geneticists other biomedical scientists research institutions policymakers students and others It will serve as a clarion call to move beyond traditional policies and practices toward a richer understanding of partnership between patients and research participants and the biomedical research enterprise a partnership for the benefit of all **Property Rights in Blood, Genes and Data** Jasper A. Bovenberg, 2006 Taking a case and context driven approach and backing up traditional legal analysis with historical analogies web surveys and practical experience Jasper Bovenberg provides counter

intuitive provocative and practical answers and recommendations for such controversial issues as how to share the benefits of DNA research whether or not to recognize personal property rights in bodily material and access to biomedical datasets in academia

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

Worst Case Bioethics George J. Annas, 2010-03-01 Bioethics still in its infancy is routinely called on by the government to provide political cover for controversial public health decisions involving the life and death of Americans Doomsday or

worst case scenarios are often at the heart of these biopolitical decisions A central feature of science fiction these scenarios can impart useful insights But worst case scenarios like Frankenstein s monster can also be unpredictably destructive undermining both preparedness and the very values bioethics seeks to promote Discovering a new flu strain for example leads immediately to visions of the 1918 flu pandemic the worst in human history Likewise a ticking time bomb scenario leads to the use of the saving lives rationale that permits lawyers to justify it and physicians to carry it out The worst case charge of death panels continues to threaten meaningful healthcare reform in the US Fundamental change in American healthcare Annas argues will require fundamental change in American including confronting our obsession with technology and our denial of death and replacing our over reliance on the military and market metaphors in medicine A combination of the ecological and rights metaphors could help us successfully navigate the waters of change In Worst Case Bioethics George Annas employs contemporary disputes involving death and disaster to explore the radical changes underway in public health practice the application of constitutional law to medicine and human rights discourse to promote human health and wellbeing Worst case scenarios especially worst case bioethics scenarios distort debate limit options rationalize human rights abuses and undermine equality and social justice It is nonetheless possible to temper worst case scenarios in ways that promote both the development of a meaningful American bioethics and a life and liberty affirming global health and human rights movement Written at the intersection of law bioethics public health and human rights Worst Case Bioethics will interest not only bioethicists but scholars in public health public policy and human rights law as well as members of the public who want to participate in these policy debates

Ethical Issues in Clinical Research Bernard Lo, 2012-03-28 This book teaches researchers how to resolve the ethical dilemmas that can arise at any stage in clinical research In addition to explaining pertinent regulations and laws Dr Lo helps investigators understand the gaps and uncertainties in regulations as well as situations in which merely complying with the law may not fulfill ethical responsibilities Most chapters include real life examples that the author walks through discussing the salient issues and how to approach them This book can be used in courses on research ethics that are required or encouraged by major National Institutes of Health grants in academic health centers

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