

CONFERENCE REPORT

Workshop of the Commission of the European Communities on Ethics of Human Genome Analysis: Survey of the European Discussion

This important EC workshop took place on 11 to 14 September 1992 in Tübingen, a delightful south German university town where one third of the population are students. It was organised by Hille Hacker, Dr Klaus Steigleder, and Professor Dietmar Mieth of the Centre of Ethics in the Sciences and Humanities. The 60 participants included eminent philosophers, theologians, ethicists, lawyers, social scientists, and medical geneticists from EC and adjoining countries. Since it was not intended that a formal statement be issued, the following is a personal compilation from five participants bringing viewpoints from ethics, medical genetics, philosophy, social science, and theology.

To many participants the essential problem to be addressed by the workshop was posed by the chairman, Dr Klaus Steigleder, who asked: "Is genome mapping compatible with individual freedom?". However, others were equally concerned with using the medical applications to relieve or prevent suffering. The scientific community looked to ethicists for assistance in reconciling these issues. An ethicist-theologian at the workshop maintained that he did not have a monopoly on ethics, but hoped to shed light and facilitate communication among participants who might then be better able to give specific attention to what is good or right in human life. Such an interdisciplinary ethical interest was evident and the variety of approaches, from biology, social sciences, and philosophy, and also the different medical and cultural contexts in European countries contributed to the general diversity of the workshop.

The philosophical context

Contributions from philosophers emphasised general issues. These concerned human dignity, the affirmation of individual freedom despite biological determinants and social constraints, the right balance between the quality of human life and its sacredness especially at its beginning, and the elucidation of real ethical questions concerning eugenics. Philosophers recognised that they must avoid an unnecessarily sensational and threatening

vision of genetics. They must also get nearer to the 'sharp edge' where advances may be implemented through the network of medical, familial, social, and economical relationships. In so doing they must define what is specific to genetic knowledge and power, for example, the fact of receiving and transmitting genes, with their qualities and defects, from and to other humans. Genetics compels us to broaden our horizons beyond isolated persons in a society, and to consider families. To be a son or daughter, a father or a mother, while being also a fellow person, represents a responsibility which transcends personal autonomy.

Medical genetics

Although there were several presentations (from the Netherlands, Switzerland, and the UK) describing health service genetic centres, discussion of them was limited by disagreement over the meaning of words like health, predictive medicine, abortion, and eugenics. Clinical geneticists had difficulty accepting the apparent rejection, or at least delay, of medically important advances because of semantic difficulties and the inchoate fear of theoretical dangers. There were many attempts to bring the discussion back to the human genome project but at no point did a consensus emerge whether this was a 'good thing' or not, and some topical issues, including germline therapy, received little attention.

Few at the workshop objected to the cost of the human genome project but many believed that it was a precursor to an inevitable return of eugenics because it would provide the rigorous science and practical techniques necessary in large scale public health strategies. Participants from the Netherlands and UK showed how a network of genetic centres, coupled with public education, provide the best protection against neo-eugenics. Properly funded genetic centres are regulated by their multidisciplinary composition and independent ethical advice. However, trained medical geneticists are few and the sheer mass of potential health and disease prevention applications will thrust increasing responsibility on a medical profession ill prepared either by training or inclination. Improving professional education is thus a matter of great urgency. Furthermore, new tests and treatments arising from the human genome project must be rigorously evaluated (validated) before widespread implementation.

Ethics Of Human Genome Analysis European Perspectives

Morton Warner, Sally Furnish, Marcus Longley, Brian Lawlor



Ethics Of Human Genome Analysis European Perspectives:

Ethics of Human Genome Analysis, 1993 *Bioethics in a European Perspective* H.A. Ten Have, Bert Gordijn, 2013-03-09

In this book developed by a group of collaborating scholars in bioethics from different European countries an overview is given of the most salient themes in present day bioethics The themes are discussed in order to enable the reader to have an in depth overview of the state of the art in bioethics Introductory chapters will guide the reader through the relevant dimensions of a particular area while subsequent case discussions will help the reader to apply the ethical theories to specific clinical problems and health policy queries The book focuses on perspectives typical for the European context This highlights not only particular bioethical themes such as social justice choices in health care and health policy e g in post communist countries it also emphasizes specific approaches in ethical theory in relation to Continental philosophies such as phenomenology and hermeneutics Because of its articulation of what is typical for the European health care setting as well as for bioethical debate this book is unique in comparison to existing textbooks in bioethics The book is an introductory textbook acquainting the reader with the major issues in present day health care as well as the various theoretical and practical approaches to clarify these issues

Ethics of Human Genome Analysis Hille Haker, Richard Hearn, Klaus Steigleder, 1993 **Bioethics in Cultural Contexts** Christoph Rehmann-Sutter, Marcus Düwell, Dietmar Mieth, 2006-03-08

CHRISTOPH REHMANN SUTTER MARCUS D WELL DIETMAR MIETH When we placed finitude limits of human existence as a motto over a round of discussion on biomedicine and bioethics which led to this collection of essays we did not know how far this would lead us into methodological quandaries However we felt intuitively that an interdisciplinary approach including social and cultural sciences would have an advantage over a solely disciplinary philosophical or theological analysis Bioethics if it is to have adequate discriminatory power should include sensitivity to the cultural contexts of biomedicine and also to the cultural contexts of bioethics itself Context awareness of course is not foreign to philosophical or theological bioethics for the simple reason that the issues tackled in the debates as in other fields of ethics could not be adequately understood outside their contexts Moral issues are always accompanied by contexts When we try to unpack them which is necessary to make them accessible to ethical discussion we are regularly confronted with the fact that in removing too much of the context we do not clarify an issue but make it less comprehensible The context at least some essential parts of it is intrinsic to the issue Unpacking in ethics is therefore a different procedure It does not mean peeling the context off but rather identifying which contextual elements are essential for an understanding of the key moral aspects of the issue and explaining how they establish its particular character

Contemporary European Perspectives on the Ethics of End of Life Care Nathan Emmerich, Pierre Mallia, Bert Gordijn, Francesca Pistoia, 2020-05-12 This book examines the ethics of end of life care focusing on the kinds of decisions that are commonly made in clinical practice Specific attention is paid to the intensification of treatment for terminal symptoms particularly pain relief and the withdrawal and withholding of care particularly life saving

or life prolonging medical care The book is structured into three sections The first section contains essays examining end of life care from the perspective of moral theory and theology The second sets out various conceptual terms and distinctions relevant to decision making at the end of life The third section contains chapters that focus on substantive ethical issues This format not only provides for a comprehensive analysis of the ethical issues that arise in the context of end of life care but allows readers to effectively trace the philosophical theological and conceptual underpinnings that inform their specific interests This work will be of interest to scholars working in the area as well as clinicians specialists and healthcare professionals who encounter these issues in the course of their practice

Ethics for Graduate Researchers Cathriona Russell, Linda Hogan, Maureen Junker-Kenny, 2012-12-31 This edited collection is intended as a primer for core concepts and principles in research ethics and as an in depth exploration of the contextualization of these principles in practice across key disciplines The material is nested so that readers can engage with it at different levels and depths It is unique in that it combines an analysis of complex ethical debates about the nature of research and its governance with the best of case based and discipline specific approaches It deals with the following topics in depth in the natural sciences it explores the scientific integrity of the researcher and the research process human cloning as a test case for the limits to research and the emerging ethical issues in nanotechnology in the health sciences it takes up the question of consent assent and proxies research with vulnerable groups and the ethics of clinical trials in the social sciences it explores the issues that arise in qualitative research interviews and ethnography and in the humanities it examines contested archaeologies and research in divided societies

Overview of Research Ethics Principles Full text papers from experienced researchers across many disciplines Dialogue with ethicists

The Ethics of Genetics in Human Procreation Hille Haker, Deryck Beyleveld, 2018-04-27 This title was first published in 2000 This third volume of proceedings of the European Network for Biomedical Ethics focuses on the ethical issues surrounding the debates on reproductive medicine and genetics in human procreation Central issues include procreation and parenthood moral protection of the human embryo and foetus autonomy and recognition social implications moral reasoning in applied ethics legal regulations of assisted procreation genetic diagnosis and gene therapy The legal regulation paper evaluates the central laws and guidelines of European countries

Ethics and Human Genetics Council of Europe, 1994

The Impact of Science and Technology on the Rights of the Individual Nicola Lucchi, 2016-06-14 The volume is devoted to the relevant problems in the legal sphere created and generated by recent advances in science and technology In particular it investigates a series of cutting edge contemporary and controversial case studies where scientific and technological issues intersect with individual legal rights The book addresses challenging topics at the intersection of communication technologies and biotech innovations such as freedom of expression right to health knowledge production Internet content regulation accessibility and freedom of scientific research

Genetics in Human Reproduction Elisabeth Hildt, Sigrid Graumann, 2018-08-13 Published in 1999 this book discusses issues related to the current and possible future

technological progress in genetic technology linked to in vitro fertilization specifically preimplantation diagnosis and germline gene therapy from a scientific and medical as well as from a social juridical and ethical point of view The 31 contributions are divided into six sections medical and scientific view personal interests and moral implications moral rights and duties social concepts and moral implications choices and decision making and justice in health care and legal regulation

The Social Management of Genetic Engineering Peter Wheale, René von Schomberg, 2019-05-23 First published in 1998 this volume why and how genetic engineering has emerged as the technology most likely to change our lives for better or worse in the opening century of the third millennium Over twenty international experts including moral philosophers and social scientists describe the issues and controversies surrounding modern biotechnology and genetic engineering They explore ways in which lay individuals and groups can join in an effective and constructive dialogue with scientists and industrialists over the assessment exploitation and safe management of these new and important technologies Topics covered include a discussion of the issues surrounding Dolly the cloned sheep the politics and ethics of the international research programme to sequence the entire human genome the ethical questions raised by the creation of transgenic farm animals the morality of genetic experimentation on animals the controversy surrounding the patenting of genetic material and of the transgenic animals themselves the ethical implications of engineering animals for transplanting their organs into humans and the environmental hazards of releasing genetically engineered organisms *Responsible Genetics* A. Nordgren, 2013-03-14

This book addresses well known issues the ethical legal and social implications of human genetics but does so from an unusual perspective the perspective of the scientific community itself In distinction to what is common in the ELSI literature the book also discusses bioethical method A new kind of casuistry is developed on the basis of the empirical findings of cognitive semantics It will be of interest to philosophers bioethicists geneticists and policymakers **Towards a Critical**

Political Ethics Hille Haker, 2020-05-13 In her book Hille Haker pleads for a radical course correction of Catholic social ethics by focusing on three foundational concepts of social ethics human rights human dignity and moral responsibility based on the interplay of compassion solidarity and justice The author argues for a historically and politically mediated ethics that replaces the natural law ethics The theoretical reflections of the book are carried out by the practical social ethical studies The politicization of individual human rights is examined in the contexts of migration religious freedom and criminal justice Human dignity is spelled out as vulnerable agency allowing for a sharp criticism of Catholic sexual morality and neglect of women s human rights The book ends with a discussion of the relationship of political theology and political ethics and its social ethical implications for the further development of a Critical Political Ethics **Medicine, Ethics and the Law in**

Ireland Deirdre Madden, 2011-01-01 Written by one of Ireland s leading medical law academics this practical book comprehensively covers Irish case law and regulations regarding the healthcare system the law relating to human reproduction and the key issues of consent and treatment Designed to be used by lawyers and healthcare professionals the

book provides an invaluable reference tool for anybody who requires accurate information and guidance on this area of Irish law This second edition covers medical research and clinical trials organ donation and transportation patient safety and biobanking Familial Cancer and Prevention Joji Utsunomiya, John J. Mulvihill, Walter Weber, 1999-04-27 A New Strategy Toward Cancer Control Still in its infancy the familial hereditary approach to cancer control is proving to be one of the most potent strategies in the war on cancer Over the past few years the human genome project has generated an abundance of valuable information on the genetic origins of a range of cancers Tests now exist for several hereditary tumor promoting genetic mutations including those found in BRCA genes associated with breast cancer as well as mutations of HNPCC genes which have been linked to colon cancers and many more are anticipated in the near future Armed with the information yielded by these tests physicians have already saved countless lives through preventative counseling early detection and more highly focused intervention strategies Inspired by the proceedings of the UICC 1997 Symposium on Familial Cancer and Prevention held in Kobe Japan this volume provides clinicians and researchers with a detailed review of the latest developments at the front lines of the familial cancer prevention movement In a series of edited contributions leading researchers and clinicians from around the globe summarize their experiences and analyze current and emerging trends in Information gathering and history taking Risk assessment Genetic testing for colorectal endocrine breast and other familial cancers Diagnosis prognosis and management of an array of familial cancers Genetic counseling for familial cancers Up to date authoritative and comprehensive Familial Cancer and Prevention is an important working resource for clinicians cancer researchers and epidemiologists Alzheimer's Disease Morton Warner, Sally Furnish, Marcus Longley, Brian Lawlor, 2020-01-31 Alzheimer s disease is becoming more common in Europe with significant human ethical economic and professional challenges to society This book examines clinical practice and service delivery and identifies policy issues that could lead to improved quality of life for sufferers and carers The book Describes the differing needs of sufferers and carers and how they can be met by a co ordinated approach to policy and implementation Outlines the particular challenges that healthcare policy makers face for this disease Shows how better models of service provision can be developed and describes best practice models Discusses the lessons to be learnt from various European pioneering projects This is a concise and practical guide for clinical specialists including psychiatrists geriatricians neurologists public health doctors nurses and policy makers and shapers in health and social services *Calling for Justice Throughout the World* Mary Jo Iozzio, Mary M. Doyle Roche, Elsie M. Miranda, 2008-01-01 Roman Catholic women theologians from all over the world discuss the HIV AIDS pandemic in terms of their particular geographical and social location **The Ethics of Genetic Engineering** Maureen Junker-Kenny, Lisa Sowle Cahill, 1998 **Owning the Genome** David B. Resnik, 2012-02-01 DNA patenting has emerged as a hot topic in science policy and bioethics as private companies and government agencies spend billions of dollars on genetic research and development in a race to identify sequence and analyze DNA from human animal and plant species David B

Resnik's *Owning the Genome* explores the ethical, social, philosophical, theological, and policy issues surrounding DNA patenting and develops a comprehensive approach to the topic. Resnik considers arguments for and against DNA patenting and concludes that only a patent on a whole human genome would be inherently immoral, while the morality of other DNA patents depends on their consequences for science, medicine, agriculture, industry, and society. He also stresses the importance of government regulations and policies in order to minimize the harmful effects of patenting while promoting the beneficial ones.

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.

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