History And Ethics Of Human Subjects Research

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The History and Ethics of Human Subjects Research: A Journey Through Time and Morality

Introduction:

The quest for medical advancement and scientific understanding has often walked a precarious tightrope, balancing the potential for groundbreaking discoveries with the ethical implications of human participation. The history of human subjects research is a complex tapestry woven with threads of both remarkable progress and egregious violations of human rights. This post delves into this intricate history, exploring key milestones, pivotal ethical breaches, and the evolving ethical frameworks that now govern research involving human participants. We'll examine how past mistakes have shaped the ethical landscape of today's research practices, ultimately aiming to provide a comprehensive understanding of the "history and ethics of human subjects research."

H2: Early Days and the Absence of Formal Ethics:

Before the establishment of formal ethical guidelines, research involving humans was often conducted with little to no consideration for participant well-being. The 18th and 19th centuries saw numerous instances where researchers, driven by a desire for knowledge, prioritized scientific advancement over the rights and safety of their subjects. Experiments were frequently performed without informed consent, often on vulnerable populations like prisoners, marginalized communities, and even children. This lack of ethical oversight led to significant harm and suffering.

H3: The Tuskegee Syphilis Study – A Dark Chapter:

The Tuskegee Syphilis Study (1932-1972) stands as a particularly egregious example of unethical research practices. In this study, African American men with syphilis were deliberately left untreated to observe the disease's natural progression. This blatant disregard for human life and dignity sparked widespread outrage and significantly impacted public trust in research institutions. The study's legacy continues to inform ethical considerations in research today.

H2: The Nuremberg Code and the Birth of Modern Ethical Standards:

The atrocities committed during the Nazi regime's medical experiments during World War II brought the urgent need for formal ethical guidelines into sharp focus. The subsequent Nuremberg Code (1947), born from the Nuremberg Trials, established ten principles for human experimentation, including voluntary consent, minimization of risk, and the right to withdraw. This code marked a pivotal moment, laying the groundwork for modern ethical standards in human subjects research.

H3: The Declaration of Helsinki and Beyond:

The World Medical Association's Declaration of Helsinki (1964, revised multiple times), further refined the ethical principles outlined in the Nuremberg Code. It emphasized the importance of independent ethical review, the protection of vulnerable populations, and the balance between the benefits of research and potential risks to participants. Subsequent documents, such as the Belmont Report (1979) in the United States, further solidified these principles and helped establish Institutional Review Boards (IRBs) to oversee research ethics.

H2: Contemporary Ethical Challenges in Human Subjects Research:

Despite significant progress in establishing ethical guidelines, contemporary research presents new and evolving ethical challenges. These include:

H3: Informed Consent in Diverse Populations:

Ensuring truly informed consent can be complex, particularly when working with diverse populations who may have varying levels of health literacy, cultural backgrounds, or language barriers.

H3: Data Privacy and Security:

The increasing use of digital technologies in research raises concerns about data privacy and security. Protecting participants' sensitive information is crucial.

H3: Research Involving Vulnerable Populations:

Ethical considerations are especially stringent when conducting research involving vulnerable populations, including children, pregnant women, prisoners, and individuals with cognitive impairments. Extra safeguards are necessary to ensure their protection.

H3: Global Research Ethics:

Conducting research across international borders presents unique ethical challenges, requiring careful consideration of cultural norms, legal frameworks, and power dynamics.

H2: The Ongoing Evolution of Ethics in Research:

The history and ethics of human subjects research continue to evolve. New technologies and research methodologies necessitate ongoing dialogue and refinement of ethical guidelines. Staying abreast of these developments is crucial for researchers, ethicists, and policymakers alike. The focus remains on ensuring that the pursuit of knowledge does not come at the expense of human dignity and well-being.

Conclusion:

The journey through the history and ethics of human subjects research highlights a stark contrast between past abuses and present-day safeguards. While the legacy of unethical practices serves as a cautionary tale, the development of robust ethical frameworks and regulatory bodies demonstrates a commitment to protecting human participants. The ongoing dialogue and refinement of ethical guidelines are essential to ensuring that future research is conducted with integrity, respect, and a unwavering commitment to human rights.

FAQs:

1. What is an Institutional Review Board (IRB)? An IRB is a committee that reviews research proposals involving human participants to ensure that the research is conducted ethically and protects the rights and well-being of participants.

2. What are the key principles of ethical research? Key principles include respect for persons (autonomy, informed consent), beneficence (maximizing benefits, minimizing harms), and justice (fair distribution of risks and benefits).

3. How has the Tuskegee Syphilis Study impacted current research practices? The Tuskegee Syphilis Study led to significant reforms in research ethics, including stricter requirements for informed consent, increased oversight by IRBs, and greater attention to the ethical treatment of vulnerable populations.

4. What are some current ethical dilemmas in human subjects research? Current ethical dilemmas include balancing research benefits with participant risks, ensuring data privacy and security, and navigating ethical complexities in global research collaborations.

5. Where can I find more information on ethical guidelines for human subjects research? Information on ethical guidelines can be found through organizations like the World Medical Association (WMA), the U.S. Department of Health and Human Services (HHS), and various national and international research ethics committees.

history and ethics of human subjects research: The Ethics of Research with Human Subjects David B. Resnik, 2018-01-09 This book provides a framework for approaching ethical and policy dilemmas in research with human subjects from the perspective of trust. It explains how trust is important not only between investigators and subjects but also between and among other stakeholders involved in the research enterprise, including research staff, sponsors, institutions, communities, oversight committees, government agencies, and the general public. The book argues that trust should be viewed as a distinct ethical principle for research with human subjects that complements other principles, such as autonomy, beneficence, non-maleficence, and justice. The book applies the principle of trust to numerous issues, including informed consent, confidentiality, risk minimization, risks and benefits, protection of vulnerable subjects, experimental design, research integrity, and research oversight.This work also includes discussions of the history of research involving human subjects, moral theories and principles, contemporary cases, and proposed regulatory reforms. The book is useful for undergraduate and graduate students studying ethical policy issues related to research with human subjects, as well as for scientists and scholars who are interested in thinking about this topic from the perspective of trust.

history and ethics of human subjects research: The Belmont Report United States. National Commission for the Protection of Human Subjects of Biomedical and Behavioral Research, 1978

history and ethics of human subjects research: Twentieth century ethics of human subjects research Volker Roelcke, Giovanni Maio, 2004 Debates on the ethics of human subjects research meet with an increasing interest both within the medical profession and the broader public. Frequently, historical arguments are used to propagate or attack certain positions within these debates. However, there is a tendency to oversimplify the complexities of the past for present day purposes, and at the same time a lack of awareness of the historical dimension implicit in today's value preferences. Twentieth Century Ethics of Human Subjects Research brings together leading historians of medicine to reconstruct and analyse the history of actual experimental practices, the debates on human subjects research, and the attempts to regulate such research during the twentieth century. The volume addresses cases of medical research in France, Britain, Israel, the United States, and Germany, including the Nazi period; the major developments of ethical debates in these and further national contexts, such as the Soviet Union, the Czech Republic, and Japan. It also explores religious views (Catholic, Jewish) on human experimentation, and the origins and contexts of international codes and declarations. Volker Roelckes Uberblick uber die Geschichte der Menschenversuche im Dritten Reich sei jedem empfohlen, der sich kurz und pragnant uber dieses dustere Kapitel deutscher Geschichte informieren mochte. FAZ.

history and ethics of human subjects research: *Research Ethics* Ana Smith Iltis, 2006-01-16 Medicine in the twenty-first century is increasingly reliant on research to guarantee the safety and efficacy of medical interventions. As a result, the need to understand the ethical issues that research generates is becoming essential. This volume introduces the principal areas of concern in research on human subjects, offering a framework for understanding research ethics, and the relationship between ethics and compliance. Research Ethics brings together leading scholars in bioethics and the topics covered include the unique concerns that arise in specific areas of research such as gene therapy and stem cell research. Individual chapters also address the ethical issues that occur when conducting research with specific populations such as infants or adolescents, and the volume looks at important emerging questions in human subjects research, namely financial conflicts of interest and the interpretation of scientific data.

history and ethics of human subjects research: *The Ethics and Regulation of Research with Human Subjects* Carl H. Coleman, Jerry Menikoff, Jesse Alan Goldner, Efthimios Parasidis, 2015

history and ethics of human subjects research: 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.

history and ethics of human subjects research: Behind Closed Doors Laura Stark, 2012-02

Drwaing on extensive archival sources, Laura Stark reconstructs the daily lives of scientists, lawyers, administrators, and research subjects working - and 'warring' - on the campus of the National Institutes of Health, where they first wrote the rules for the treatment of human subjects.

history and ethics of human subjects research: Genetics Robert J. Brooker, 2005

history and ethics of human subjects research: International Ethical Guidelines for Biomedical Research Involving Human Subjects Council for International Organizations of Medical Sciences, 2002 The present text is the revised/updated version of the CIOMS International Ethical Guidelines for Biomedical Research Involving Human Subjects. It consists of 21 guidelines with commentaries. A prefatory section outlines the historical background and the revision process and includes an introduction an account of earlier instruments and guidelines a statement of ethical principles and a preamble. An Appendix lists the items to be included in the research protocol to be submitted for scientific and ethical review and clearance. The Guidelines relate mainly to ethical justification and scientific validity of research; ethical review; informed consent; vulnerability - of individuals groups communities and populations; women as research subjects; equity regarding burdens and benefits; choice of control in clinical trials; confidentiality; compensation for injury; strengthening of national or local capacity for ethical review; and obligations of sponsors to provide health-care services. They are designed to be of use to countries in defining national policies on the ethics of biomedical research involving human subjects applying ethical standards in local circumstances and establishing or improving ethical review mechanisms. A particular aim is to reflect the conditions and the needs of low-resource countries and the implications for multinational or transnational research in which they may be partners.

history and ethics of human subjects research: Understanding Clinical Research Renato D. Lopes, Robert A. Harrington, 2013-05-22 A complete guide to understanding and applying clinical research results Ideal for both researchers and healthcare providers Understanding Clinical Research addresses both the operational challenges of clinical trials and the needs of clinicians to comprehend the nuances of research methods to accurately analyze study results. This timely resource covers all aspects of clinical trials--from study design and statistics to regulatory oversight--and it delivers a detailed yet streamlined overview of must-know research topics. The text features an accessible three-part organization that traces the evolution of clinical research and explains the bedrock principles and unique challenges of clinical experimentation and observational research. Reinforcing this content are real-life case examples--drawn from the authors' broad experience--that put chapter concepts into action and contribute to a working knowledge of integral research techniques. FEATURES: The most definitive guide to promoting excellence in clinical research, designed to empower healthcare providers to assess a study's strengths and weaknesses with confidence and apply this knowledge to optimize patient outcomes In-depth coverage of fundamental research methods and protocols from preeminent authorities provides readers with an instructive primer and a springboard for ongoing clinical research education Clear, comprehensive three-part organization: Section One: Evolution of Clinical Research offers a succinct history of clinical trials, drug regulations, and the role of the FDA while covering the impact of information technology and academic research organizations Section Two: Principles of Clinical Experimentation takes you through the typical phases of clinical trials in the development of medical products, from initial human subject research to postapproval surveillance studies Section Three: Observational Research highlights the underlying principles, pitfalls, and methods for case-control studies, cohort studies, registries, and subgroup analyses within randomized trials

history and ethics of human subjects research: The Handbook of Social Research Ethics Donna M. Mertens, Pauline E. Ginsberg, 2009 Brings together international scholars across the social and behavioural sciences and education to address those ethical issues that arise in the theory and practice of research within the technologically advancing and culturally complex world in which we live.

history and ethics of human subjects research: *Women and Health Research* Institute of Medicine, Committee on Ethical and Legal Issues Relating to the Inclusion of Women in Clinical

Studies, 1994-02-01 In the nineteenth century some scientists argued that women should not be educated because thinking would use energy needed by the uterus for reproduction. The proof? Educated women had a lower birth rate. Today's researchers can only shake their heads at such reasoning. Yet professional journals and the popular press are increasingly criticizing medical research for ignoring women's health issues. Women and Health Research examines the facts behind the public's perceptions about women participating as subjects in medical research. With the goal of increasing researchers' awareness of this important topic, the book explores issues related to maintaining justice (in its ethical sense) in clinical studies. Leading experts present general principles for the ethical conduct of research on womenâ€principles that are especially important in the light of recent changes in federal policy on the inclusion of women in clinical research. Women and Health Research documents the historical shift from a paternalistic approach by researchers toward women and a disproportionate reliance on certain groups for research to one that emphasizes proper access for women as subjects in clinical studies in order to ensure that women receive the benefits of research. The book addresses present-day challenges to equity in four areas: Scientificâ€Do practical aspects of scientific research work at cross-purposes to gender equity? Focusing on drug trials, the authors identify rationales for excluding people from research based on demographics. Social and Ethicalâ€The authors offer compelling discussions on subjectivity in science, the evidence for male bias, and issues related to race and ethnicity, as well as the recruitment, retention, and protection of research participants. Legalâ€Women and Health Research reviews federal research policies that affect the inclusion of women and evaluates the basis for researchers' fears about liability, citing court cases. Riskâ€The authors focus on risks to reproduction and offspring in clinical drug trials, exploring how risks can be identified for study participants, who should make the assessment of risk and benefit for participation in a clinical study, and how legal implications could be addressed. This landmark study will be of immediate use to the research community, policymakers, women's health advocates, attorneys, and individuals.

history and ethics of human subjects research: *Registries for Evaluating Patient Outcomes* Agency for Healthcare Research and Quality/AHRQ, 2014-04-01 This User’s Guide is intended to support the design, implementation, analysis, interpretation, and quality evaluation of registries created to increase understanding of patient outcomes. For the purposes of this guide, a patient registry is an organized system that uses observational study methods to collect uniform data (clinical and other) to evaluate specified outcomes for a population defined by a particular disease, condition, or exposure, and that serves one or more predetermined scientific, clinical, or policy purposes. A registry database is a file (or files) derived from the registry. Although registries can serve many purposes, this guide focuses on registries created for one or more of the following purposes: to describe the natural history of disease, to determine clinical effectiveness or cost-effectiveness of health care products and services, to measure or monitor safety and harm, and/or to measure quality of care. Registries are classified according to how their populations are defined. For example, product registries include patients who have been exposed to biopharmaceutical products or medical devices. Health services registries consist of patients who have had a common procedure, clinical encounter, or hospitalization. Disease or condition registries are defined by patients having the same diagnosis, such as cystic fibrosis or heart failure. The User’s Guide was created by researchers affiliated with AHRQ’s Effective Health Care Program, particularly those who participated in AHRQ’s DEcIDE (Developing Evidence to Inform Decisions About Effectiveness) program. Chapters were subject to multiple internal and external independent reviews.

history and ethics of human subjects research: The Ethics Police? Robert Klitzman, 2015 Studies on humans have saved countless lives, but sometimes harm participants. Research ethics committees currently monitor scientists, but have been increasingly criticized for blocking important research. How these committees work, however, is largely unknown. This book uniquely illuminates this hidden world that ultimately affects us all.

history and ethics of human subjects research: International Ethical Guidelines for

Health-Related Research Involving Humans Council for International Organizations of Medical Sciences (CIOMS), 2017-01-31 In the new 2016 version of the ethical guidelines, CIOMS provides answers to a number of pressing issues in research ethics. The Council does so by stressing the need for research having scientific and social value, by providing special guidelines for health-related research in low-resource settings, by detailing the provisions for involving vulnerable groups in research and for describing under what conditions biological samples and health-related data can be used for research.--Page 4 de la couverture.

history and ethics of human subjects research: Ethics by Committee Noortje Jacobs, 2022-08-26 Ethics boards have become obligatory passage points in today's medical science, and we forget how novel they really are. The use of humans in experiments is an age-old practice that records show goes back to at least the third century BC and, since the early modern period, as a practice it has become increasingly popular. Yet, in most countries around the world, hardly any formal checks and balances existed to govern the communal oversight of experiments involving human subjects until at least the 1960s. Ethics by Committee traces the rise of ethics boards for human experimentation in the second half of the twentieth century. Using the Netherlands as a case-study, Noortje Jacobs shows how the authority of physicians to make decisions about clinical research gave way in most developed nations to formal mechanisms of communal decision-making that served to regiment the behavior of individual researchers. This historically unprecedented change in scientific governance came out of a growing international wariness of medical research in the decades after World War II. Research ethics committees were originally intended not only to make human experimentation more ethical but also to raise its epistemic quality. By examining complex negotiations over the appropriate governance of human subjects research, Ethics by Committee advances our understanding not only of the history of research ethics and the randomized controlled trial but also, more broadly, of how liberal democracies in the late twentieth century have sought to resolve public concerns over charged issues in medicine and science--

history and ethics of human subjects research: *Ethical Conduct of Clinical Research Involving Children* Institute of Medicine, Board on Health Sciences Policy, Committee on Clinical Research Involving Children, 2004-07-09 In recent decades, advances in biomedical research have helped save or lengthen the lives of children around the world. With improved therapies, child and adolescent mortality rates have decreased significantly in the last half century. Despite these advances, pediatricians and others argue that children have not shared equally with adults in biomedical advances. Even though we want children to benefit from the dramatic and accelerating rate of progress in medical care that has been fueled by scientific research, we do not want to place children at risk of being harmed by participating in clinical studies. Ethical Conduct of Clinical Research Involving Children considers the necessities and challenges of this type of research and reviews the ethical and legal standards for conducting it. It also considers problems with the interpretation and application of these standards and conduct, concluding that while children should not be excluded from potentially beneficial clinical studies, some research that is ethically permissible for adults is not acceptable for children, who usually do not have the legal capacity or maturity to make informed decisions about research participation. The book looks at the need for appropriate pediatric expertise at all stages of the design, review, and conduct of a research project to effectively implement policies to protect children. It argues persuasively that a robust system for protecting human research participants in general is a necessary foundation for protecting child research participants in particular.

history and ethics of human subjects research: Ethics and Regulation of Clinical Research Robert J. Levine, 1988-01-01 The use of human subjects in medical and scientific research has given rise to troubling ethical questions. How should human subjects be selected for experiments? What should they be told about the research in which they are involved? How can their privacy be protected? When is it permissible to deceive them? How do we deal with subjects such as children, fetuses, and the mentally infirm, for whom informed consent is impossible? In this book, Dr. Robert J. Levine reviews federal regulations, ethical analysis, and case studies in an attempt to answer these questions. His book is an essential reference for everyone--members of institutional review boards, scientists, philosophers, lawyers--addressing the ethical issues involved. [Levine's] experience as a clinician, IRB chairman, writer and editor of a journal devoted exclusively to issues faced by IRBS makes him uniquely qualified to bring together the legal, ethical, and practical dimensions. . . [The book] is sophisticated but readable. . . [and] should be on every IRB administrator's desk and in every medical ethics library.--Norman Fost, M.D., The New England Journal of Medicine Levine. . . is one of the foremost historians of contemporary clinical science. . . . His book is at once a guide to primary sources for the history of clinical research in the late twentieth century and a pioneering secondary source about that history.--Daniel M. Fox, Bulletin of the History of Medicine You will be charmed by the [book's] elegance and lucidity and. . . persuaded of its relevance to doctors in any country.--Alex Paton, British Medical Journal Should be of wide interest to those keen to see advances in medical research brought into general medical practice.--Gilbert Omenn, Issues in Science and Technology

history and ethics of human subjects research: Ethical and Regulatory Aspects of Clinical Research Ezekiel J. Emanuel, 2003 Professionals in need of such training and bioethicists will be interested.

history and ethics of human subjects research: Ethical Considerations for Research Involving Prisoners Committee on Ethical Considerations for Revisions to DHHS Regulations for Protection of Prisoners Involved in Research, Board on Health Sciences Policy, Institute of Medicine, 2007-01-22 In the past 30 years, the population of prisoners in the United States has expanded almost 5-fold, correctional facilities are increasingly overcrowded, and more of the country's disadvantaged populations—racial minorities, women, people with mental illness, and people with communicable diseases such as HIV/AIDS, hepatitis C, and tuberculosis—are under correctional supervision. Because prisoners face restrictions on liberty and autonomy, have limited privacy, and often receive inadequate health care, they require specific protections when involved in research, particularly in today's correctional settings. Given these issues, the Department of Health and Human Services' Office for Human Research Protections commissioned the Institute of Medicine to review the ethical considerations regarding research involving prisoners. The resulting analysis contained in this book, Ethical Considerations for Research Involving Prisoners, emphasizes five broad actions to provide prisoners involved in research with critically important protections: • expand the definition of prisoner; • ensure universally and consistently applied standards of protection; • shift from a category-based to a risk-benefit approach to research review; • update the ethical framework to include collaborative responsibility; and • enhance systematic oversight of research involving prisoners.

history and ethics of human subjects research: *History and Theory of Human Experimentation* Ulf Schmidt, 2007 Despite having been revised and criticised over the years, the Declaration of Helsinki remains one of the most important and internationally known ethics codes worldwide. Yet we know relatively little about its historical origins or about the prolonged revision process which accompanied this living document. The chapters presented in this volume look at the history and theory of human experimentation, assess the role of the Helsinki Declaration in an international context, and illustrate specific issues about the history and practice of research ethics through a number of case studies in the United States, Asia and Europe. To this day, the Declaration is one of the most important landmarks in human subject research which is aimed at protecting experimental subjects in society. The current volume offers a better and historically-informed understanding of the Declaration to ensure that the existing safeguards are not only preserved but developed and improved in the future. Die 1964 veroffentlichte Deklaration zu Helsinki ist einer der wichtigsten und international bekanntesten Kodizes zur Forschungsethik, dessen Entstehungsgeschichte von steter Kritik und zahlreichen Uberarbeitungen begleitet wurde. Dennoch weiss man relativ wenig uber die historischen Wurzeln und Novellierungsprozesse dieses gewachsenen Dokuments der Medizingeschichte. Bis zum heutigen Tag ist die Deklaration einer der bedeutendsten Wegweiser fur die Forschung am Menschen, deren grundsatzliches Ziel es ist, Versuchspersonen in medizinischen Experimenten zu schutzen. Der Band beleuchtet Geschichte und Theorie der Experimente am Menschen, untersucht die Rolle der Deklaration im internationalen Kontext und illustriert spezifische Themen zur Geschichte und Praxis der Forschungsethik anhand von Fallstudien zu den USA, Asien und Europa. Ausserdem geben die Studien Einblick in die Entstehungsgeschichte der Deklaration - nicht nur um die bestehenden Standards zum Schutz von Versuchspersonen zu bewahren, sondern auch um diese zukunftig weiterzuentwickeln und zu verbessern. Aus dem Inhalt Ulf Schmidt / Andreas Frewer: History and Ehtics of Human Experimentation: the Twisted Road to Helsinki. An Introduction History and Theory of Medical Research Ethics Ulrich Trohler: The Long Road of Moral Concern: Doctors' Ethos and Statute Law Relating to Human Research in Europe Dietrich von Engelhardt: The Historical and Philosophical Background of Ethics in Clinical Research Ulf Schmidt: The Nuremberg Doctors' Trial and the Nuremberg Code Till Barnighausen: Communicating Tainted Science The Japanese Biological Warfare Experiments on Human Subjects in China The Helsinki Declaration in an International Context Susan E. Lederer: Research Without Borders: The Origins of the Declaration of Helsinki Povl Riis: Forty Years of the Declaration of Helsinki: Progress in Medical Ethics? Kati Myllymaki: Revising the Declaration of Helsinki: An Insiders' View Robert Carlson / Kenneth Boyd / David Webb: The Interpretation of Codes of Medical Ethics: Some Lessons from the Fifth Revision of the Declaration of Helsinki David Willcox: Medical Ethics and Public Perception: The Declaration of Helsinki and its Revisions in 2000 Dominique Sprumont / Sara Girardin / Trudo Lemmens: The Helsinki Declaration and the Law: An International and Comparative Analysis History and Ethics of Research - International Perspectives Andreas Frewer: History of Medicine and Ethics in Conflict: Research on National Socialism as Moral Problem Ulf Schmidt: Medical Ethics and Human Experiments at Porton Down: Informed Consent in Britain's Biological and Chemical Warfare Experiments John Williams: The Declaration of Helsinki. The Importance of Context Jonathan D. Moreno: Helsinki into the Future. An Epilogue Key Documents on the History of Research Ethics Circular of the Reich Minister of the Interior Concerning Guidelines for New Therapy and Human Experimentation (Berlin, 1931) - The Nuremberg Code (1947) - World Medical Association: Declaration of Helsinki I (1964) - World Medical Association: Declaration of Helsinki II (Tokyo, 1975) - Council of Europe: Convention on Human Rights and Biomedicine (Oviedo, 1997) - World Medical Association: Declaration of Helsinki (2004)

history and ethics of human subjects research: The Cambridge World History of Medical Ethics Robert B. Baker, Laurence B. McCullough, 2009 The Cambridge World History of Medical Ethics provides the first global history of medical ethics.

history and ethics of human subjects research: The Immortal Life of Henrietta Lacks Rebecca Skloot, 2010-02-02 #1 NEW YORK TIMES BESTSELLER • “The story of modern medicine and bioethics—and, indeed, race relations—is refracted beautifully, and movingly.”—Entertainment Weekly NOW A MAJOR MOTION PICTURE FROM HBO® STARRING OPRAH WINFREY AND ROSE BYRNE • ONE OF THE “MOST INFLUENTIAL” (CNN), “DEFINING” (LITHUB), AND “BEST” (THE PHILADELPHIA INQUIRER) BOOKS OF THE DECADE • ONE OF ESSENCE’S 50 MOST IMPACTFUL BLACK BOOKS OF THE PAST 50 YEARS • WINNER OF THE CHICAGO TRIBUNE HEARTLAND PRIZE FOR NONFICTION NAMED ONE OF THE BEST BOOKS OF THE YEAR BY The New York Times Book Review • Entertainment Weekly • O: The Oprah Magazine • NPR • Financial Times • New York • Independent (U.K.) • Times (U.K.) • Publishers Weekly • Library Journal • Kirkus Reviews • Booklist • Globe and Mail Her name was Henrietta Lacks, but scientists know her as HeLa. She was a poor Southern tobacco farmer who worked the same land as her slave ancestors, yet her cells—taken without her knowledge—became one of the most important tools in medicine: The first “immortal” human cells grown in culture, which are still alive today, though she has been dead for more than sixty years. HeLa cells were vital for developing the polio vaccine; uncovered secrets of cancer, viruses, and the atom bomb’s effects; helped lead to important advances like in vitro fertilization, cloning, and gene mapping; and have been bought and sold by the billions. Yet Henrietta Lacks remains virtually unknown, buried in an unmarked grave. Henrietta’s family did not learn of her “immortality” until more than twenty years after her death, when scientists investigating HeLa began using her husband and children in research without informed consent. And though the cells had launched a multimillion-dollar industry that sells human biological materials, her family never saw any of the profits. As Rebecca Skloot so brilliantly shows, the story of the Lacks family—past and present—is inextricably connected to the dark history of experimentation on African Americans, the birth of bioethics, and the legal battles over whether we control the stuff we are made of. Over the decade it took to uncover this story, Rebecca became enmeshed in the lives of the Lacks family—especially Henrietta’s daughter Deborah. Deborah was consumed with questions: Had scientists cloned her mother? Had they killed her to harvest her cells? And if her mother was so important to medicine, why couldn’t her children afford health insurance? Intimate in feeling, astonishing in scope, and impossible to put down, The Immortal Life of Henrietta Lacks captures the beauty and drama of scientific discovery, as well as its human consequences.

history and ethics of human subjects research: Experimentation with Human Subjects Paul Abraham Freund, 1970 Most of the essays appeared in the spring 1969 issue of Dædalus.

history and ethics of human subjects research: *National Statement on Ethical Conduct in Human Research 2023* National Health and Medical Research Council (Australia), Australian Research Council, Universities Australia, 2023 The purpose of the National Statement is to promote ethically good human research. Fulfilment of this purpose requires that participants be accorded the respect and protection that is due to them. It also involves the fostering of research that is of benefit to the community. The National Statement is therefore designed to clarify the responsibilities of: institutions and researchers for the ethical design, conduct and dissemination of results of human research ; and review bodies in the ethics review of research. The National Statement will help them to meet their responsibilities: to identify issues of ethics that arise in the design, review and conduct of human research, to deliberate about those ethical issues, and to justify decisions about them--Page 6.

history and ethics of human subjects research: Institutional Review Board Member Handbook Robert J. Amdur, Elizabeth A. Bankert, 2010-10-22 The Essential Resource for All IRB Members! Designed to give Institutional Review Board (IRB) members the information they need to protect the rights and welfare of research subjects in a way that is both effective and efficient, the chapters of the Institutional Review Board Member Handbook are short and to the point. Topic-specific chapters list the criteria IRB members should use to determine how to vote on specific kinds of studies and offer practical advice on what IRB members should do before and during full-committee meetings. NEW CHAPTERS in this Edition Include: * Definition of Human Subject Research, Exempt & Expedited Review Categories * IRB Member Conflict of Interest All chapters are completely updated for 2010 practice! This handbook is an excellent accompaniment to Institutional Review Board: Management and Function, Second Edition and the Study Guide that IRB members can access and refer to quickly and easily.

history and ethics of human subjects research: Returning Individual Research Results to Participants National Academies of Sciences, Engineering, and Medicine, Health and Medicine Division, Board on Health Sciences Policy, Committee on the Return of Individual-Specific Research Results Generated in Research Laboratories, 2018-08-23 When is it appropriate to return individual research results to participants? The immense interest in this question has been fostered by the growing movement toward greater transparency and participant engagement in the research enterprise. Yet, the risks of returning individual research resultsâ€such as results with unknown validityâ€and the associated burdens on the research enterprise are competing considerations. Returning Individual Research Results to Participants reviews the current evidence on the benefits, harms, and costs of returning individual research results, while also considering the ethical, social, operational, and regulatory aspects of the practice. This report includes 12 recommendations directed to various stakeholdersâ€investigators, sponsors, research institutions, institutional review boards (IRBs), regulators, and participantsâ€and are designed to help (1) support decision making regarding the return of results on a study-by-study basis, (2) promote high-quality individual research results, (3) foster participant understanding of individual research results, and (4) revise and harmonize current regulations.

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