history and ethics of human subjects research

history and ethics of human subjects research have shaped the foundation of modern science, clinical practice, and public trust in research. This article examines the evolution of human subjects research, highlighting key historical events, ethical milestones, and the development of regulatory frameworks. Readers will gain insights into major ethical principles, infamous cases that spurred reform, the role of institutional review boards, and ongoing ethical challenges in contemporary research. By understanding the past and present of human subjects research, professionals and the public alike can appreciate the importance of protecting participants and promoting responsible scientific advancement. Continue reading to discover the critical moments, core principles, and future directions that define the history and ethics of human subjects research.

Origins and Early History of Human Subjects Research

Early Experiments and Medical Advances

The history and ethics of human subjects research trace back centuries, with early medical experiments often lacking formal oversight or ethical standards. Initial research involving human subjects was driven by the pursuit of knowledge and medical breakthroughs, ranging from the testing of new treatments to the observation of disease progression. These early studies were pivotal in advancing medicine but occasionally subjected individuals to significant risks without their informed consent.

Societal Attitudes Toward Experimentation

In previous centuries, there was limited awareness of the moral implications of using human beings as research subjects. Societal attitudes often prioritized scientific progress over individual rights, especially among marginalized populations. Vulnerable groups—including prisoners, orphans, and the poor—were frequently selected for research due to their perceived expendability and lack of power. This period set the stage for the development of the ethical principles that now guide human subjects research.

Notorious Cases and Scandals in Human Research

The Nuremberg Trials and Nazi Experiments

The aftermath of World War II revealed horrific abuses in the

History And Ethics Of Human Subjects Research

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.

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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.

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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

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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.

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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.

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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)

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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.

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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.

history and ethics of human subjects research: The Oxford Handbook of Public Health Ethics Anna C. Mastroianni, Jeffrey P. Kahn, Nancy E. Kass, 2019-07-23 Natural disasters and cholera outbreaks. Ebola, SARS, and concerns over pandemic flu. HIV and AIDS. E. coli outbreaks from contaminated produce and fast foods. Threats of bioterrorism. Contamination of compounded drugs. Vaccination refusals and outbreaks of preventable diseases. These are just some of the headlines from the last 30-plus years highlighting the essential roles and responsibilities of public health, all of which come with ethical issues and the responsibilities they create. Public health has achieved extraordinary successes. And yet these successes also bring with them ethical tension. Not all public health successes are equally distributed in the population; extraordinary health disparities between rich and poor still exist. The most successful public health programs sometimes rely on policies that, while improving public health conditions, also limit individual rights. Public health practitioners and policymakers face these and other questions of ethics routinely in their work, and they must navigate their sometimes competing responsibilities to the health of the public with other important societal values such as privacy, autonomy, and prevailing cultural norms. This Oxford Handbook provides a sweeping and comprehensive review of the current state of public health ethics, addressing these and numerous other questions. Taking account of the wide range of topics under the umbrella of public health and the ethical issues raised by them, this volume is organized into fifteen sections. It begins with two sections that discuss the conceptual foundations, ethical tensions, and ethical frameworks of and for public health and how public health does its work. The thirteen sections that follow examine the application of public health ethics considerations and approaches across a broad range of public health topics. While chapters are organized into topical sections, each chapter is designed to serve as a standalone contribution. The book includes 73 chapters covering many topics from varying perspectives, a recognition of the diversity of the issues that define public health ethics in the U.S. and globally. This Handbook is an authoritative and indispensable guide to the state of public health ethics today.

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have historically been prey to grave-robbing as well as unauthorized autopsies and dissections. Moving into the twentieth century, it shows how the pseudoscience of eugenics and social Darwinism was used to justify experimental exploitation and shoddy medical treatment of Blacks. Shocking new details about the government's notorious Tuskegee experiment are revealed, as are similar, less-well-known medical atrocities conducted by the government, the armed forces, prisons, and private institutions. The product of years of prodigious research into medical journals and experimental reports long undisturbed, Medical Apartheid reveals the hidden underbelly of scientific research and makes possible, for the first time, an understanding of the roots of the African American health deficit. At last, it provides the fullest possible context for comprehending the behavioral fallout that has caused Black Americans to view researchers—and indeed the whole medical establishment—with such deep distrust.

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