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ID #	Title	Author	Year Published	SUMMARY
1	Chronic Fatigue Syndrome - A Victim's Guide To Understanding, Treating, & Coping With This Debilitating Illness	Gregg Charles Fisher with Stephen E. Straus, M.D., Paul R. Cheney, MD, Ph.D., James M. Oleske	1989	Tragically, the tormenting exhaustion and painful debilitation of chronic fatigue syndrome does not stop with the sufferer. A disease that not only invades, but envelops, CFS has paralyzing symptoms that can affect the entire family, stretching the family finances - and the bonds of love - to the breaking point. Yet, the lives and relationships of CFS sufferers can be healed - even as they wait for a cure to be found for this insidious disease. Drawn from the challenges and triumphs posed by Gregg Fisher's own seven-year struggle with CFS, and culled from the findings of the most respected medical authorities in the field, this timely and compassionate guide empowers CFS sufferers and those who love them to: (1) strengthen support systems while allowing the patient to heal; (2) maintain financial security and well-being no matter how prolonged the illness; (3) seek out the treatments that can bolster the immune system without depleting morale; (4) move beyond the grief, guilt, and anger that isolate CFS victims in their pain; (5) and, most of all, live each day as fully...
2	Planning Ethically Responsible Research - A Guide for Students and Institutional Review Boards	Joan E. Sieber	1992	This book was written to provide social scientists, their students, and members of research ethics committees with the theory and practical knowledge needed to plan ethically responsible social and behavioral research. It interprets current viewpoints on what ethical research is, especially those views presented in The Belmont Report (National Commission, 1978), a document set forth by the National Commission on the Protection of Human Subjects of Biomedical and Behavioral Research. It is also a practical handbook on how to translate ethical principles into valid research methods and procedure that satisfy both scientific and ethical standards. Part of each chapter provide guidelines for satisfying federal regulations governing human research and for working with one's Institutional Review Board (IRB), or Human Subjects Committee, as such groups are variously...
3	Protecting Study Volunteers in Research - A Manual for Investigative Sites	Cynthia McGuire Dunn, MD& Gary Chadwick, Pharm.D., MPH	1999	The intent of this manual is to aid researchers in understanding the regulatory requirements and ethical principles upon which they are based. The manual will also identify issues that require sensitivity when designing or conducting human research studies. Ultimately the safety and welfare of human subjects rests in the hands of the investigators. We hope this manual will aid all members of the research community in promoting ethical scientific discovery.
4	Clinical Ethics - Fourth Edition	Albert R. Jonsen, Mark Siegler, William J. Winslade	1998	We have two purposes in writing this book: first, to offer an approach that facilitates thinking about the complexities of the problems that clinicians actually face and, second, to assemble concise representative opinions about typical ethical problems that occur in the practice of medicine. Our book is intended not only for clinicians and students who provide care to patients, but also for others whose work requires an awareness and sensitivity to the ethical issues raised in clinical care, such as hospital chaplains, administrators, hospital attorneys, members of institutional ethics committees, quality reviewers, and administrators of health plans.
5	A Short History of Medical Ethics	Albert R. Jonsen	2000	A physician says, "I have an ethical obligation never to cause the death of a patient," another responds, "My ethical obligation is to relieve pain even if the patient dies." The current argument over the role of physicians in assisting patients to die constantly refers to the ethical duties of the

				<p>profession. References to the Hippocratic Oath are often heard. Many modern problems, from assisted suicide to accessible health care, raise questions about the traditional ethics of medicine and the medical profession. However, few know what the traditional ethics are and how they came into being. This book provides a brief tour of the complex story of how medical ethics evolved over centuries in both Western and Eastern culture. It sets this story in the social and cultural contexts in which the work of healing was practiced and suggest that, behind the many different perceptions about the ethical duties of physicians, certain themes appear constantly, and may be relevant to modern debates. The book begins with the Hippocratic medicine of ancient Greece, moves through the Middle Ages, Renaissance and Enlightenment in Europe, and the long history of Indian and Chinese medicine, ending as the problems raised in modern medical science and technology challenge the settled ethics of long tradition. Two chapters record the growth of medical ethics in the environment of American medicine. The final chapter chronicles the events in medical science and technology that began to transform medical ethics into bioethics.</p>
6	Ethics of Research with Human Subjects - Selected Policies and Resources	Jeremy Sugarman, Anna C. Mastroianni, Jeffrey P. Kahn	1998	<p>This book should be useful for IRB members and administrators, scholars, students, researchers, and those responsible for research oversight in various settings. This book is divided into three parts. Part 1: Landmark Documents, contains materials that have in some way influenced policy development related to research with human subjects. Part 2: Selected Major Policies, presents important policies relating to this research. These include policies that address general issues arising in the context of research with human subjects, as well as those addressing particular subject populations and research settings. Part 3: Selected Bibliography, provides citations to resources that are intended to amplify understanding of policies for human subjects research and, perhaps more importantly, address gaps where policy guidance is lacking.</p>
7	Ethics and Regulation of Clinical Research	Robert J. Levine	1988	<p>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 analyses, 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.</p>
8	Beyond Consent - Seeking Justice in Research	Jeffrey P. Kahn, Anna C. Mastroianni, Jeremy Sugarman	1998	<p>Beyond Consent examines the concept of justice, and its application to research with human subjects, through the lenses of research populations: children, the vulnerable sick (including those seeking emergency medical care), captive and convenient populations (such as prisoners), women, people of color, and subjects in emergency and international settings. To set the stage for this examination, an introductory chapter addresses the evolution of research policies. After a look at specific subject populations and settings, concluding chapters discuss the concept of justice with respect to research with human subjects and examines its implications for this research in the future. The editors, in addition to authoring chapters of their own, have assembled a team of eight other contributors, all of whom are leading experts in the ethics of research with human subjects.</p>
9	Undue Risk - Secret State Experiments on Humans	Jonathan D. Moreno	2000	<p>In Undue Risk, Moreno presents the first comprehensive history of the use of human subjects in atomic, biological, and chemical warfare experiments from World War II to the twenty-first century. From the courtrooms of Nuremberg to the battlefields of the Gulf War, Undue Risk explores a variety of government policies and specific cases, including plutonium injections into unwitting hospital patients, U.S. government attempts to recruit Nazi medical scientists, the subjection of soldiers to atomic blast fallout, secret LSD and mescaline studies, and the feeding of irradiated oatmeal to children. It is the first book to go behind the scenes and reveal the government's struggle with the ethics of human experimentation and the evolution of agonizing policy choices on unfamiliar moral terrain.</p>
10	Acres of Skin - Human Experiments at Holmesburg Prison	Allen M. Hornblum	1998	<p>At a time of increased interest and renewed shock over the Tuskegee syphilis experiments, Acres of Skin sheds light on yet another dark episode of American medical history. In this disturbing expose, Allen M. Hornblum tells the story of Philadelphia's Holmesburg Prison. From the early 1950s through the mid-1970s, Holmesburg's inmates were used, in exchange for a few dollars, as guinea pigs in a host of medical experiments. Acres of Skin argues that at Holmesburg the American medical establishment betrayed</p>

				<p>the ideals of the Hippocratic Oath and the Nuremberg Code. An array of doctors, in conjunction with the University of Pennsylvania and prison officials, established Holmesburg as a laboratory testing ground. Hundreds of prisoners were used to test products from facial creams and skin moisturizers to perfumes, detergents, and anti-rash treatments. Other experiments used the inmates as test subjects for far more hazardous, even potentially lethal, substances such as radioactive isotopes, dioxin, and chemical warfare agents. Based on in-depth interviews with dozens of prisoners as well as the doctors and prison officials who, respectively, performed and permitted these experimental tests, Hornblum paints a disturbing portrait of abuse, moral indifference, and greed. Central to this account are the millions of dollars many of America's leading drug and consumer goods companies made available for the eager doctors seeking fame and fortune through their medical experiments. Many of these doctors established their illustrious careers on the backs of the inmates who served as the ideal test subjects - isolated, ...</p>
11	Oral History and the Law - Revised Edition - Oral History Association Pamphlet Series No. 1	John A. Neuenschwander	1993	<p>Oral History and the Law first appeared in 1985; this edition is expanded and revised to reflect the increasing complexity of case law regarding oral history and other historical materials in recent ...</p>
12	Title Using Oral History in Community History Projects - Oral History Association Pamphlet Series #4	Laurie Mercier and Madeline Buckendorf	1992	<p>Because good planning is the key to a successful community oral history project, we provide a detailed, step-by-step guide to project planning and execution in Section 1. Section 2 addresses common pitfalls that may arise in an oral history project and suggests ways to avoid or minimize them. Section 3 describes the successful use of oral history in a number of community history projects. The final section is a bibliography of publications providing specific guidance about oral history methods and means of interpretation. In this pamphlet, we describe how an oral history project can be set up and carried out as part of a community history project. For some projects, oral history will be the primary means of gathering information; for other projects, oral history will be used as part of a larger data-gathering effort. The suggestions we provide are applicable in both cases. We hope that those who are new to community oral history projects can learn from the experiences of others who have already struggled around (and sometimes through) the quicksands associated with these endeavors. The suggestions presented here are based on such experiences.</p>
13	The Ethics of Research Involving Human Subjects - Facing the 21st Century	Harold Y. Vanderpool	1996	<p>This book is about the current status and future directions of the ethics of research involving human subjects. Medical researchers, members and administrators of institutional review boards (IRBs) in academia and industry, ethicists, government officials, and informed citizens face a maze of changes and challenges over the ethics and regulation of biomedical research. These are the persons for whom this book is written. Its chapter depict where we are and envision where we are going. As is primary objective, this books seeks to make sense of an almost overwhelming body of literature and regulation on research ethics. Each of the book's contributors is a leader in his or her field of inquiry. Each author deals with a critical feature of contemporary research ethics. To capture current trends, many of the essays are arranged in a debate-like format. Different points of view are juxtaposed, and at points the authors of this volume address or oppose the positions of their fellow authors. Finally, this book serves as a bibliographical and document resource. Each chapter and introduction points to pivotal sources and background discussions. Each references the latest literature in its field of inquiry. The appendices contain critically important documents in the ethics and regulation of past and present ...</p>
14	Research Ethics - Cases & Materials	Robin Levin Penslar	1995	<p>Research Ethics is a comprehensive resource for classroom discussion of research ethics in the natural sciences, the behavioral sciences, and the humanities. The materials selected for inclusion here can speak to people in all disciplines, though the cases are drawn from biology, psychology, and history. They cover such topics as plagiarism, confidentiality, conflict of interest, fraud and misconduct, access to research materials, the obligations of mentors and teachers, the reporting of data, and the participation of human and animal subjects in research. Specific pedagogical suggestions for many of the cases are provided in the instructional notes. In addition, Research Ethics provides a discussion of ethical theory and pedagogy. An annotated bibliography will help instructors identify resources to use as supplements to cases, assist readers who are</p>

				developing courses in research ethics, and aid further research on the ...
15	Human Subjects Research - A Handbook for Institutional Review Boards	Robert A. Greenwald, Mary Kay Ryan, and James E. Mulvihill	1982	Human Subjects Research is designed to fill the need for a practical guide to IRB function. It covers ethical and operational principles and summarizes the review process and procedures for submitting research proposals. The procedures, recommendations, and suggestions put forth in this volume are based on the final set of regulations published in the Federal Register on January 26 and 27, 1981. Topics covered range from everyday concerns to such especially difficult problems as studies involving children, surgical research, and the use of placebos in drug trials. A useful appendix, with samples of approved consent forms, continuing review forms, and forms to be submitted to government agencies, and an annotated bibliography complete the volume. Broadly based and widely applicable, this handbook will provide IRB members and staff, as well as researchers engaged in biomedical, behavioral, and social science research, with guidelines for thoughtfully and effectively carrying out their IRB responsibilities.
16	Interpreting the Federal Code for Human Subjects Research - The Burden of Protection	See Summary	1991	Audio tapes featuring: (Tape 1) Workshop Overview: What are the Principles of the Belmont Report? (F. William Dommel, Jr.) and FDA Regulatory Update (FDA Representative); (Tape 2) Beneficence: Keynote Address (Charles R. McCarthy), Risk Assessment & Confidentiality (Ernest Kraybill), Vulnerable Subject Populations (Mario Perez-Reyes), and Justification for Expanded Availability of Drugs (FDA Representative); (Tape 3 - 2 tapes) Respect for Persons: Keynote (Steven Hauerwas), Modes of Consent (Thomas Wallsten), Recruitment Issues (Mark Hollins), and Clarity of Informed Consent & Deception (James Hunt); (Tape 4) Justice: Keynote (F. William Dommel), Institutional Interactions (Thomas Petrick), The Role of the IRB When Things Go Wrong (Susan Enringhaus), and Criteria for Exclusion/Inclusion of Subjects (Inge Corless); (Tape 5) IRB Membership & Composition (Tom Scott), IRB Role & Authorities (Clifford C. Sharke), IRB Review Procedures (Carl Shy), and IRB Recordkeeping Requirements (Susan Bauer); (Tape 6) Mock IRB Session Reviewing Protocols; (Tape 7) IRB's in the 1990's (Charles R. McCarthy).
17	The Spirit Catches You and You Fall Down	Anne Fadiman	1997	The Spirit Catches You and You Fall Down explores the clash between a small county hospital in California and a refugee family from Laos over the care of Lia Lee, a Hmong child diagnosed with severe epilepsy. Lia's parents and her doctors both wanted what was best for Lia, but the lack of understanding between them led to tragedy.
18	To Know Ourselves - The US Department of Energy and The Human Genome Project	Multiple Contributors	1996	Discusses the Human Genome Project undertaken in 1986 by the US Department of Energy.
19	Exploring Public Policy Issues in Genetics	Mark S. Frankel	1996	A compilation of presentations and resource materials prepared as part of a congressional seminar series on the human genome project.
20	Hanford Medical Monitoring Program: Background Consideration Document and ATSDR Decision	Robert F. Spengler, ScD	1997	In determining whether a medical monitoring program is appropriate for Hanford, the Agency for Toxic Substances and Disease Registry (ATSDR) first had to determine whether specific criteria had been met. This document presents the information that was used to determine if the criteria were met and if the logistics of a proposed program might be...
21	The Abuse of Casuistry - A History of Moral Reasoning	Albert R. Jonsen & Stephen Toulmin	1988	In this book we begin by exploring more deeply the implications of this distinction between science and prudence, intellectual theory and practical understanding. Taking this as our point of departure, we may then venture out to meet the attacks on casuistry and case ethics with greater confidence; and we can even go over to the counterattack. For (it turns out) the arguments by which Blaise Pascal and his successors have brought the enterprise of casuistry into disrepute contain, in turn, their own fundamental flaw, one that Aristotle would have recognized, only to deplore. Even now, we shall argue, the rejection of case ethics is a lingering expression of the intellectual dream that, after all, ethics may yet be transformed into a universal theoretical science. And that (we shall see) is precisely what, from the outset, Aristotle's distinction between episteme and phronesis, or between scientific understanding and practical wisdom, was designed to undercut.
22	Research Involving	National Bioethics	1999	Volume II - Commissioned Papers by the National Bioethics Advisory

	Persons with Mental Disorders That May Affect Decisionmaking Capacity	Advisory Commission		Commission.
23	Research Involving Persons With Mental Disorders That May Affect Decisionmaking Capacity	National Bioethics Advisory Commission	1998	Volume I - Report and Recommendations of the National Bioethics Advisory Commission.
24	Final Report - Advisory Committee on Human Radiation Experiments	Advisory Committee on Human Radiation	1995	The main part of the text is divided into four parts. Each part is preceded by an overview. Part I, "Ethics of Human Subjects Research: A Historical Perspective," which contains four chapters, explores how both federal government agencies and the medical profession approached human experimentation in the period 1944 through 1974. Part II, "Case Studies," approaches particular experiments from several angles, each of which raises overlapping ethical questions. Part III, "Contemporary Projects," reports the findings of our three inquiries into the present. Part IV, "Coming to Terms with the Past, Looking Ahead to the Future," reports the Committee's findings and recommendations.
25	Protecting Human Rights	National Institutes of Health and the Food and Drug Administration	1986	Video containing three parts: Evolving Concern - Protection for Human Subjects (traces the development of today's comprehensive program to protect human subjects of research out of earlier ethical codes and societal concerns); Balancing Society's Mandates - Criteria for Protocol Review (depicts an Institutional Review Board in action); and The Belmont Report - Basic Ethical Principles and Their Application (describes the basic ethical principles that underlie research involving human subjects: respect for persons, beneficence, and justice).
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27	A Stampede of Zebras	The National Science Foundation	1996	Video - Scientific Integrity and Ethics of Research
28	Ethical and Policy Issues in International Research: Clinical Trials in Developing Countries	National Bioethics Advisory Commission	2001	A binder containing both Volumes I and II. Volume I discusses the ethical issues that arise when research that is subject to US regulation is sponsored or conducted in developing countries. Volume II contains five expert papers, including three empirical studies of international perspectives that helpfully assisted the commission in its...
29	Creating an Ethical Framework for Studies That Involve the Worker Community	Human Subjects Research Program, Office of Biological and Environmental Research (SC-72), Office of Science, and US Department of Energy	2000	The purpose of An Ethical Framework for Studies That Involve the Worker Community is to raise the awareness of all stakeholders to the special needs and issues that apply to research using workers as study subjects.
30	1998 Program Book Supplement - Occupational Energy Research Program	Health-Related Energy Research Branch - Division of Surveillance, Hazard Evaluations and Field Studies	1998	This guide simply and effectively communicates the purpose, variety and content of the NIOSH/HERB Occupation Radiation Research Program. This resource identifies the major research issues within each project and also contains the name of the DOE sites or facilities where each study is being...
31	Occupational Energy Research Program	Health-Related Energy Research Branch - Division of Surveillance, Hazard Evaluations and Field Studies	1998	Presents an overview of the occupational health research program conducted under the 1996 Memorandum of Understanding (MOU) between the Department of Energy (DOE) and the Department of Health and Human Services (DHHS). The reader will find information addressing studies conducted internally by NIOSH staff; studies conducted externally through NIOSH supported contracts, grants, and cooperative agreements; DOE

worker surveillance projects with NIOSH involvement; and administrative and programmatic details within this document.

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