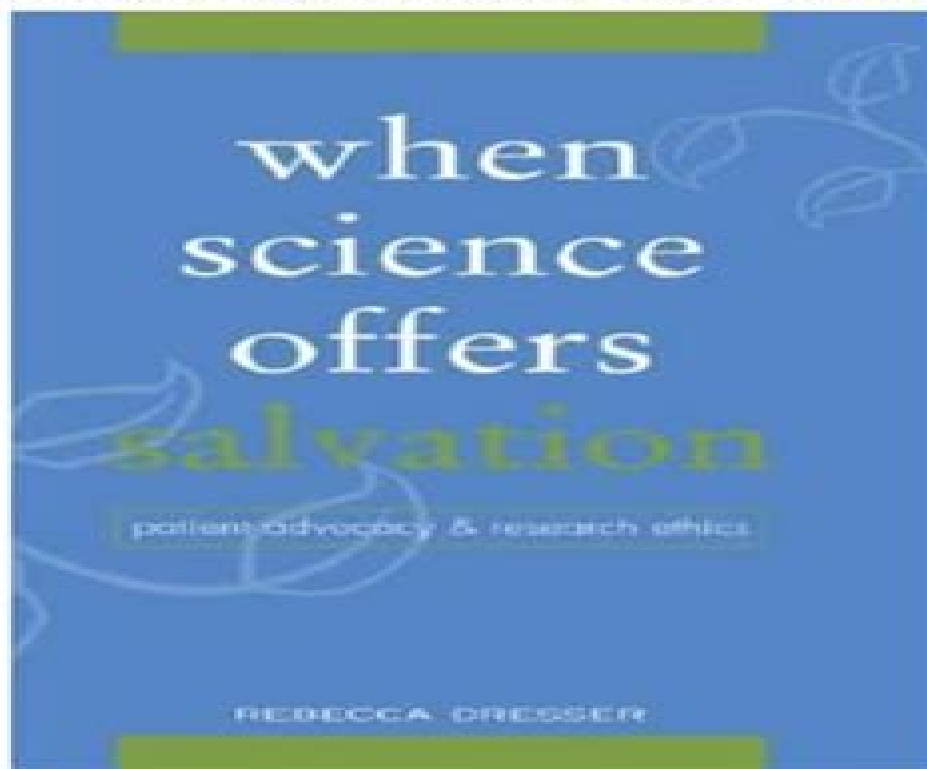


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Rebecca Susan Dresser



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When Science Offers Salvation Rebecca Dresser, 2001-03-22 Patient advocates can help make research more ethical but advocacy raises ethical issues of its own

When Science Offers Salvation Rebecca Susan Dresser, 2023 In examining how advocates have transformed health research the author of this study examines patient advocacy through the lens of research ethics

When Science Offers Salvation Rebecca Dresser, 2001-03-22 Biomedical research today has a high public profile largely because of patient advocacy Following in the footsteps of HIV AIDS activists advocates representing an array of patient groups are now vocal partners in the research enterprise Advocates want research practices and policies to be more responsive to the people who must live with the burdens of illness This book shows how advocates have transformed health research often but not always for the better Dresser is the first to examine patient advocacy through the lens of research ethics She reveals the many ways in which a quest for cures and improved therapies shapes advocacy work She exposes the bright and dark sides of patients expanded opportunities to enroll in clinical trials and join researchers in planning and evaluating studies She considers the virtues and drawbacks of giving patients more influence over how the government invests its research dollars She argues that advocates should do more to promote ethical human studies and responsible media reporting about research Patient advocates can help make research more ethical but advocacy raises ethical issues of its own This book clearly and vividly recounts the advocacy contribution to research and explores the thorny ethical issues facing research advocates

The Oxford Handbook of Research Ethics Ana S. Iltis, Douglas MacKay, 2024 The development of new pharmaceutical products and behavioral interventions aimed at improving people's health as well as research that assesses the efficacy and cost effectiveness of public policies such as policies designed to improve children's education or reduce poverty depends on research conducted with human participants It is imperative that research with human subjects is conducted in accordance with sound ethical principles and regulatory requirements Featuring 45 original essays by leading research ethicists The Oxford Handbook of Research Ethics offers a critical overview of the ethics of human subjects research within multiple disciplines and fields including biomedicine public health psychiatry sociology political science and public policy

Gene Transfer and the Ethics of First-in-Human Research Jonathan Kimmelman, 2010 Human gene transfer is widely regarded as one of the most promising technologies for the treatment of a variety of disorders but it presents practitioners with a variety of difficult ethical questions Gene Transfer and the Ethics of First in Human Research examines the ethical and policy dimensions of testing interventions in human beings for the first time The book discusses the difficult ethical challenges that arise from attempting to translate laboratory discoveries into clinical applications These range from which available techniques to use when to initiate human testing questions of consent expectation in public arenas how to define acceptable risk and the inclusion of vulnerable or disadvantaged subjects in early phase trials This book is relevant to ethicists legal practitioners policy makers geneticists and clinicians involved in clinical

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

Silent Partners Rebecca Dresser, 2017 The research ethics system was created without the help of people who know what it is like to be a research subject This is a serious omission Experts have overlooked ethical issues that matter to subjects Silent Partners moves subjects to the forefront giving them a voice in research ethics

Revival: Human Experimentation and Research (2003) George F. Tomossy, David N. Weisstub, 2017-07-12 This title was first published in 2003 As new medical technologies and treatments develop with increasing momentum the legal and ethical implications of research involving human participants are being called into question as never before Human Experimentation and Research explores the philosophical foundations of research ethics ongoing regulatory dilemmas and future challenges raised by the rapid globalisation and corporatisation of the research endeavour This volume brings together some of the most significant published essays in the field The editors also provide an informative introduction summarizing the area and the relevance of the articles chosen

Ethical Issues in Cardiovascular Medicine David M. Zientek, Mark J. Cherry, 2021-11-29 This book provides an exploration of the ethics of cardiology practice It provides a variety of frameworks for analyzing ethical issues that arise in cardiovascular medicine Cardiovascular medicine the diagnosis and treatment of congenital and acquired diseases of the heart major arteries and veins has seen rapid change in diagnosis treatment and the organization of practice in the last half of the twentieth and the beginning of the twenty first century The complexity of these developments has resulted in increasing subspecialization and many practitioners are challenged to stay abreast with the latest developments in cardiology These changes also bring with them various ethical challenges The chapters in this volume are divided by five broad areas of practice beginning of life end of life transplantation and allocation of expensive or scarce resources professionalism and research The case based approach presented across the volume provides a perspective that will allow readers to reason through current and future ethical issues as they arise in this rapidly changing field Ethical Issues in Cardiovascular Medicine will be of interest to researchers working in bioethics clinical ethics and the philosophy of medicine as well as practicing physicians nurses and students who work in cardiovascular medicine

The Blackwell Guide to Medical Ethics Rosamond Rhodes, Leslie P. Francis, Anita Silvers, 2008-04-15 The Blackwell Guide to Medical Ethics is a guide to the complex literature written on the increasingly dense topic of ethics in relation to the new technologies of medicine Examines the key ethical issues and debates which have resulted from the rapid advances in biomedical technology

Brings together the leading scholars from a wide range of disciplines including philosophy medicine theology and law to discuss these issues Tackles such topics as ending life patient choice selling body parts resourcing and confidentiality Organized with a coherent structure that differentiates between the decisions of individuals and those of social policy

Playing Politics with Science David B. Resnik, 2009-01-20 In the last decade science in the United States has become increasingly politicized as government officials have been accused of manipulating distorting subverting and censoring science for ideological purposes Political gamesmanship has played a major role in many different areas of science including the debate over global climate change embryonic stem cell research government funding of research the FDA's approval process military intelligence related to Iraq research with human subjects and the teaching of evolution in public schools In *Playing Politics with Science* David B Resnik explores the philosophical political and ethical issues related to the politicalization of science and develops a conceptual framework for thinking about government restrictions on scientific practice Resnik argues that the public has a right and a duty to oversee scientific research to protect important social values and hold scientists accountable for their actions but that inappropriate government control over science can erode the integrity and trustworthiness of research hamper scientific creativity and innovation undermine the fairness and effectiveness of government and policies informed by science discourage talented researchers from working for the government and violate the freedom of scientists Resnik also makes policy recommendations for protecting science from politicalization and maintains that scientific autonomy and government control must be properly balanced so that restrictions on science can benefit society without undermining scientific research education and expert advice

Medical Research for Hire Jill A. Fisher, 2008-11-06 Today more than 75 percent of pharmaceutical drug trials in the United States are being conducted in the private sector Once the sole province of academic researchers these important studies are now being outsourced to non academic physicians According to Jill A Fisher this major change in the way medical research is performed is the outcome of two problems in U S health care decreasing revenue for physicians and decreasing access to treatment for patients As physicians report diminishing income due to restrictive relationships with insurers increasing malpractice insurance premiums and inflated overhead costs to operate private practices they are attracted to pharmaceutical contract research for its lucrative return Clinical trials also provide limited medical access to individuals who have no or inadequate health insurance because they offer free doctors visits diagnostic tests and medications to participants Focusing on the professional roles of those involved as well as key research practices Fisher assesses the risks and advantages for physicians and patients alike when pharmaceutical drug studies are used as an alternative to standard medical care A volume in the *Critical Issues in Health and Medicine* series edited by Rima D Apple and Janet Golden

A Humanistic Approach to Health Promotion David R. Buchanan, 2020-11-25 This book presents a distinct ethically robust framework for improving population health when the major causes of disease death and disability are closely associated with human behaviors Rather

than relying on a scientific technological strategy aimed at developing ever more powerful and effective techniques for changing behaviors a humanistic approach recognizes the unique human capacity for dignity and moral decision making As an essential alternative to the scientific assumption of determinism a humanistic framework is based on the equally viable assumption that human beings have the capacity to exercise autonomy in pursuing their life plans If people can choose how they want to live their lives then it is imperative to respect and cultivate their autonomy in making health promoting decisions A scientific approach is unsurpassed at identifying effective means for stopping and killing bacteria the same methods are not appropriate however when the objective is to alter human behavior In a humanistic framework it is important to acknowledge that autonomous choices are not completely unrestrained the human condition has significant physical and social limitations and that certain readily identifiable social groups face much greater constraints than others most significantly due to poverty and racism As explained and justified in this book the most important task for health promotion is to promote autonomy and to do this by redressing the hugely disparate yet corrigible barriers faced by people occupying distinct social positions This project is a matter of social justice not a scientific and technological problem to be solved but a moral and political endeavor to engage fellow citizens in strengthening our social institutions to enable everyone to realize their innate capacities to the fullest extent possible The book provides ethical standards case studies and concrete practical analogies to demonstrate the feasibility and benefits of moving the field of health promotion in a new humanistic direction

Extraordinary Risks, Ordinary Lives Beata Świtek, Allen Abramson, Hannah Swee, 2022-03-25 This book untangles the relationship between expert categorisations of risk and the on the ground experiences of untrained ordinary people who may be routinely subjected to significant danger in a variety of extraordinary contexts It considers political ethical and moral dimensions of risk and calls for more targeted ethnographic research designed to reveal how grass roots risk dispositions and practice intersect with official discourses individual agency and community resilience [Handbook of Community-Based Participatory Research](#)

[Handbook of Community-Based Participatory Research](#) Steven S. Coughlin, Selina A. Smith, Maria E. Fernandez, 2017-01-11 Community based participatory research CBPR emerged in response to the longstanding tradition of top down research studies in which social scientists observe social phenomena and community problems as outsiders separate from the participants daily lives CBPR is more immersive fostering partnerships between academic and community organizations that increase the value and consequence of the research for all partners The current perspectives gleaned from this school of research have been wildly well received in no small part because they address the complexity of the human experience in their conclusions HANDBOOK OF COMMUNITY BASED PARTICIPATORY RESEARCH codifies the methods and theories of this research approach and articulates an expansive vision of health that includes gender equality safe and adequate housing and freedom from violence Topic based chapters apply the theory and methods of CBPR to real world problems affecting women ethnic and racial minorities and immigrant communities such as sexual violence exposure to environmental toxins and lack of access to

preventive care as well as suggesting future directions for effective culturally sensitive research

HANDBOOK OF COMMUNITY BASED PARTICIPATORY RESEARCH is required reading for academics policy makers and students seeking meaningful social change through scholarship

The Limits of Consent Oonagh Corrigan, 2009-01-29 Since its inception as an international principle to protect the welfare of patients and volunteers taking part in medical research informed consent has become increasingly important within healthcare Despite its ubiquitous status there are a number of scholars who are beginning to question whether consent is adequate for contemporary biomedical research The Limits of Consent considers a number of criticisms that have been levelled at the prominence given to autonomy a central tenet underpinning the rationale for informed consent in Western bioethics It raises questions about how quickly and easily this principle has been adopted and how appropriate it is for those actively engaged in research In the context of genetic research for example the individual's overriding right of autonomy to give consent to research could have huge implications for other members of their families The Limits of Consent questions the assumption that informed consent protects or facilitates individual autonomy and discusses empirical studies which suggest that gaining a truly informed consent can be difficult to achieve in practice With the expectation of treatment and guidance from the physician how much is the process of consent governed by social norms and expectations The Limits of Consent focuses upon three principal areas within biomedical research clinical trials genetic research and research with those who may have impaired capacity to consent It is a truly multi disciplinary book incorporating perspectives from medicine law philosophy and sociology The Limits of Consent is a fascinating exploration of the inadequacies of consent and will appeal to those in the fields of bioethics socio legal studies sociology and health law Policy makers research ethics committee members and those healthcare professionals with an interest in medical ethics will also find the book of interest

Pharmacogenetics: Making cancer treatment safer and more effective William G. Newman, 2010-07-20 Chemotherapy has made a dramatic difference to improved survival in patients with cancer However not all patients respond and some experience serious side effects Pharmacogenetics Making cancer treatment safer and more effective is an up to date summary of the exciting new field of how genetic testing can tailor more effective prescription in oncology It is targeted at oncologists and professionals involved in the treatment of patients with cancer It provides a core background in genetics and pharmacological principles before providing chapters from acknowledged experts in the field on genetic tests in specific cancer types including breast bowel and lung cancer Clinical cases are used to illustrate the practical application of this knowledge Chapters on ethics health economics and the industry aspects of pharmacogenetics set out the challenges and opportunities afforded by this new science

The New Economics of Technology Policy Dominique Foray, 2009 This innovative book comprehensively sheds light on the theory and practice of technological policies by employing modern analytical tools and economic techniques The New Economics of Technology Policy focuses on all public interventions intended to influence the intensity composition and direction of technological innovations within a given entity

such as a region country or group of countries Dominique Foray has gathered together many of the leading scholars in the field to comprehensively explore numerous avenues and pathways of research Bringing together a collection of policy oriented papers this book will strongly appeal to policy makers academic researchers and graduate students with an interest in economics public policy science technology and society Genetic Databases Oonagh Corrigan, Richard Tutton, 2004 Genetic Databases offers a timely analysis of the underlying tensions contradictions and limitations of the current regulatory frameworks for and policy debates about genetic databases Drawing on original empirical research and theoretical debates in the fields of sociology anthropology and legal studies the contributors to this book challenge the prevailing orthodoxy of informed consent and explore the relationship between personal privacy and the public good They also consider the multiple meanings attached to human tissue and the role of public consultations and commercial involvement in the creation and use of genetic databases The authors argue that policy and regulatory frameworks produce a representation of participation that is often at odds with the experiences and understandings of those taking part The findings present a serious challenge for public policy to provide mechanisms to safeguard the welfare of individuals participating in genetic databases The New Blackwell Companion to Medical Sociology William C. Cockerham, 2016-09-26 An authoritative topical and comprehensive reference to the key concepts and most important traditional and contemporary issues in medical sociology Contains 35 chapters by recognized experts in the field both established and rising young scholars Covers standard topics in the field as well as new and engaging issues such as bioterrorism bioethics and infectious disease Chapters are thematically arranged to cover the major issues of the sub discipline Global range of contributors and an international perspective

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