

# SETTING ALLOCATION PRIORITIES GENETIC AND REPRODUCTIVE TECHNOLOGIES

*Emerging Issues  
in Biomedical Policy*

VOLUME I

ROBERT H. BLANK AND  
ANDREA L. BONNICKSEN

# Emerging Issues In Biomedical Policy An Annual Review

**United States. Food and Drug  
Administration**



## **Emerging Issues In Biomedical Policy An Annual Review:**

*AIDS Bibliography*, 1995-05      **Health and the New Media** Linda M. Harris, 2013-11-05 This book presents an evaluation framework for assessing the impact of the new media on the health care system by juxtaposing characteristics of emerging information and communication technologies interactive seamlessly connected and user driven and health care objectives to increase access improve quality and manage costs Each chapter provides a unique set of tools and perspectives on how to harness these new media to improve individual health and the health care delivery system This innovative volume has also stimulated the creation of a Forum on Health and the New Media on the World Wide Web <http://Health.Dartmouth.edu/NewMedia> The forum offers highlights of the book as well as links to the authors and related web sites The volume is divided into six sections as follows The Overview juxtaposes characteristics of the new media interactive connected and user driven with the three criteria for health care improvement increased access improved quality and cost management It offers a New Media and Health Care matrix of criteria for building and evaluating emerging health care systems The Delivery how new media can enhance the delivery of health care includes chapters on managed care demand management and self care telemedicine for rural residents and how the Internet can be used to facilitate collaboration among health researchers and providers Health Information the life blood of health care addresses the potential for extending the traditional flow of health information from researchers to providers to reach patients who want to share in decisions about their care and the federal government's role in providing health information to the public Health Education discusses integrating multimedia health programming for public schools using networked multimedia and simulation technologies and new learning theories that promise to transform public health education and educating health providers and patients through interactive media and drama Potholes Along the Highway provides a sobering balance to otherwise rather optimistic assumptions that a national information infrastructure will be forthcoming The New Media Annotated Glossary provides computing and networking technology tools for readers who are not fluent in cyberlanguage      *Outreach Notebook for the NIH Guidelines on Inclusion of Women and Minorities as Subjects in Clinical Research* National Institutes of Health (U.S.), 1994      **The Rise and Fall of HMOs** Jan Coombs, 2005 Drawing upon a wealth of research Coombs compares HMOs throughout the nation with the one in Marshfield which came as close as any HMO to realizing the ideal of early advocates This book is a resource for specialists in the fields of health policy research and analysis health care management health law and politics public health and social and organizational history of medicine It will also appeal to many readers who are disturbed by the current state of America's health care system and are curious about its future **BOOK JACKET**      **Current Issues in Human Subject Protection** United States. Food and Drug Administration, 1996      *Setting Allocation Priorities* Robert H. Blank, Andrea L. Bonnicksen, 1993-11-24 Volume 1 discusses the problems inherent in allocating limited biomedical technologies whose needs take precedence what individual rights and responsibilities are involved and when societal good justifies restricting

individual good Volume Two focuses on whether and when life extending technologies should be used or withdrawn

**Emerging Issues in Biomedical Policy** Robert H. Blank, Andrea L. Bonnicksen, 1992      **Beyond Regulations** Nancy M. P. King, Gail E. Henderson, Jane Stein, 2005-10-12 Across a broad range of disciplines in medicine social science and the humanities researchers scholars teachers and administrators increasingly are looking for new ways to approach ethical issues in research with human subjects Questions about how relationships between funders and researchers should affect research design for example or whether the potential benefits of research can outweigh the importance of its subjects interests are inadequately addressed by the prevailing regulation based research ethics paradigm This book constitutes a reexamination of research ethics It combines case studies and commentaries by a multidisciplinary group of scholars and researchers to explore such topics as informed consent conflict of interest confidentiality and research on illegal behavior All human subjects research takes place within complex social cultural and political contexts the contributors argue Increased consideration of the relationships between researchers and their subjects funders and institutions within these contexts will facilitate research that is sensitive and responsible as well as scientifically fruitful Beyond Regulations features a keynote essay by Ruth Macklin Other contributors are Marcela Aracena Alvarez Jorge Balan B Susan Bauer Alan F Benjamin Lynn Blanchard Allan M Brandt J Pat Browder Barbara Entwisle Sue E Estroff Renee C Fox Lara Freidenfelds Gail E Henderson Nancy M P King Loretta M Kopelman Ernest N Kraybill Barry M Popkin Silvina Ramos Desmond K Runyan Jane Stein Ronald P Strauss Keith A Wailoo and Cynthia Waszak Across a broad range of disciplines in biomedicine the social sciences and the humanities researchers scholars administrators and teachers increasingly struggle with questions of ethics in research with human subjects All research takes place in complex social cultural political and economic contexts yet the prevailing principle based research ethics paradigm does not adequately account for them This book reexamines research ethics using a new relationships paradigm Through in depth cases commentaries and essays a multidisciplinary group of scholars and researchers addresses informed consent conflict of interest confidentiality and other issues considering questions like What relationships should researchers have with their subjects communities When researchers and subjects have different views about research who should have control How should relationships between funders and researchers affect research design Can research be so potentially beneficial that its importance outweighs the interests of subjects Examining the relationships between researchers and subjects communities funders and institutions including considerations of authority and voice can facilitate human subjects research that is morally sensitive and responsible as well as scientifically fruitful      **Making Sense of Advance Directives** Nancy M.P. King, 1996-02-01 Advance directives such as living wills and health care proxies are documents intended to declare and preserve the health care choices of patients if they become unable to make their own decisions This book provides a comprehensive overview of advance directives and clear practical directions for writing and interpreting them Nancy M P King provides a legal philosophical and historical analysis of the moral and legal force of

advance directives She explains the types and models of advance directives currently in use and offers guidelines for individuals seeking to write read and use directives to promote individuals health care choices within the laws of their own states King emphasizes that advance directives are not orders given by patients to their doctors instead they are documents that invite conversation between doctors and patients about health care decisions of great importance The purpose of advance directives is to support patients health care choices and the book promotes a thoughtful use of advance directives that is best calculated to achieve that purpose whatever form individual advance directives may take This new edition has been updated to reflect the many changes in advance directive statutes since 1991 including expanded discussions of health care proxy statutes the impact of the Patient Self Determination Act and the Supreme Court s Cruzan decision King also has extended her analysis of the implications for advance directives of managed care resource allocation resource scarcity and the debate over futile treatment at the end of life Making Sense of Advance Directives is a valuable handbook for patients health care providers and administrators patient counselors lawyers policymakers and any individual interested in advance directives

Race & Research Bettina M. Beech, Maurine Goodman, 2004 Race and Research Perspectives on Minority Participation in Health Studies is a teaching text and resource guide for students health professionals public health researchers and the general public that extends the discussion of environmental factors that influence ethnic minority participation in health studies This book examines the lack of minority participation in health studies from social historical and scientific perspectives This book is divided into three main sections 1 The Meaning of Race Culture and Ethnicity in Research 2 Health Studies and Ethnic Minority Populations and 3 The Impact of Revolutionary Changes in Medicine and Health Care on Minority Participation in Health Studies *Outreach Notebook for the Inclusion, Recruitment and Retention of Women and Minority Subjects in Clinical Research* National Institutes of Health (U.S.), 2002

**Negotiating Health Care** Sally E. Thorne, 1993-03-24 Contributing a unique perspective to health reform Negotiating Health Care presents the findings of a large qualitative investigation of the experiences of the chronically ill within today s health care system The author develops the argument that chronic illness and acute illness are social experiences of a vastly different order that lead to different health care consequences especially in a health system geared to the miracle cure From interviews with chronically ill patients Thorne discusses the onset of their diseases handling acute episodes and their attempts to normalize life The author also examines the interpersonal experience with health care providers exploring the issues of trust confidence and compliance The institutional experience can and often does pose daunting problems for the chronically ill because of organizational and sociocultural issues health care politics and ideology and the individual patient s response to the system In her concluding chapter Thorne proposes future directions for health care organization biomedical technology and social policy Students and professionals in the fields of nursing allied health medical sciences and human services will find Negotiating Health Care a valuable resource This book is highly recommended for all health care professionals and anyone

involved in legislation regarding chronic health care on a national basis The book also could be very useful for lay people who are chronically ill and for their caregivers and families Rehabilitation Nursing Finally a window is opened to the experience of chronic illness as it exists within the North American health care system Just in time Every health care provider and reformer who looks inside will be changed by the reflections of themselves they see This book is a courageous voice for both the bolder more conclusive clinical research and for the chronically ill who may yet show us a better way William L Miller M D The University of Connecticut Although there are a number of texts available on chronic illness Dr Thorne s approach to the topic is unique in that it provides a graphic illustration of how the beliefs and values guiding the health care system contribute to problems which the chronically ill encounter in obtaining care By setting the experience of chronic illness in the broader context of the health care system the book provides some clear guidelines for needed changes something I have not found elsewhere This is a valuable piece of work which is a valuable contribution to our understanding of chronic illness and which provides a guide both to practice and to health policy revision Lee Walker R N Ph D The University of Utah This extraordinary book provides rich description and unique insights into the illness experience Data obtained from interviews with 91 informants provides remarkable detail strong linkages to existing theory and powerful development of the illness trajectory The book is well documented methodologically rigorous and presented in a refreshing style Dr Thorne has written a classic Negotiating Health Care will become the book of the 90s for anyone interested in providing humanistic care Jan Morse R N Ph D College of Health and Human Development The Pennsylvania State University The book provides a view into the major issues adults with chronic illness experience in obtaining health care a perspective that is rarely available to those of use who use the health care system mainly for acute problems or indeed who are the providers The book is powerful intense and often uncomfortable reading the patients own words should sensitize all of us who work with the chronically ill Verbatim accounts of patients experiences are woven into a lucid and perceptive view of the structure and organization of Canadian health care which should be read by health policymakers in all the western industrialized countries Juliene G Lipson Ph D F A A N University of California San Francisco Thorne takes a unique approach in providing a graphic illustration of how the beliefs and values guiding the health care system contribute to the problems the chronically ill encounter in obtaining care Those concerned with the evolving social and health policy in the United States would be well served in reading Negotiating Health Care Academic Library Book Review

**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 women 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 Scientific 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 Ethical 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 Legal 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 Risk 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

New and Emerging Issues in Latinx Health Airín D. Martínez, Scott D. Rhodes, 2019-08-19 This volume is being published at a critical time in U S history and serves as a comprehensive and much needed update to what is known about Latinx health As both the United States and Latinx subgroups experience demographic shifts it is critical to examine the current epidemiology of Latinx health as well as the factors influencing the health and well being of this growing population Chapters in this book written by highly respected experts illuminate the diversity of the Latinx population and provide strategies to mitigate many of the challenges they face including challenges related to migrating to new destinations The book is designed to enrich dialogue around the multilevel determinants of Latinx health and concludes with a call to action for increased culturally congruent theoretically informed and participatory Latinx health research The book also encourages the mentorship and growth of early career and junior investigators to conduct research on Latinx health issues A selection of the perspectives included among the chapters Chronic disease and mental health issues in Latinx populations Substance use among Latinx adolescents in the United States Physical and intellectual and developmental disabilities in Latinx populations Health insurance reform and the Latinx population Immigration enforcement policies and Latinx health Research priorities for Latinx sexual and gender minorities Racial and ethnic discrimination intersectionality acculturation and Latinx health New and Emerging Issues in Latinx Health is an invaluable compendium that provides a foundation of understanding Latinx health and well being and guides future research and practice The book is essential for researchers

practitioners and students in the fields of public health and the social sciences including community and health psychology health administration and policy community health education medical anthropology medical sociology population health and preventive medicine Moreover the chapters in this volume are also relevant for federal state and local agencies including health departments and other Latinx and immigrant serving community organizations

**Beyond Consent** Jeffrey P. Kahn, Anna C. Mastroianni, Jeremy Sugarman, 1998-09-03 Patients with cancer and AIDS now clamor for access to clinical trials Federal policies governing research that once emphasized protecting subjects from dangerous research now promote access to clinical research Have claims about justice and access to the benefits of research eclipsed concerns about consent and protection from risks How can we make good and fair decisions about the selection of subjects and other questions of justice in research *Beyond Consent* examines the concept of justice and its application to human subject research through the different lenses of important research populations children the vulnerable sick captive and convenient populations women people of color and subjects in international settings To set the stage for this examination and introductory chapter addresses the evolution of research policies After a look at specific subject populations the authors discuss the concept of justice for research with human subjects in the future and analyze justice throughout the research enterprise

**The New Politics of State Health Policy** Robert B. Hackey, David A. Rochefort, 2001 State governments in the past decade have had to take on the problem of health care with mixed results This collection of 11 essays of which two are an introduction and conclusion by academics and policy makers consider the many issues that concern health care in the US and their effects at the state level including managed care health insurance expansion mental health care public health administration and bureaucratic reactions to health policy Hackey teaches health policy and management at Providence College in Rhode Island Rochefort teaches political science and public administration at Northeastern U in Boston c Book News Inc

**Canadian Community as Partner** Ardene Robinson Vollman, Elizabeth T. Anderson, Judith M. McFarlane, 2007-10-01 This is the Canadian adaptation of the Fifth Edition of the AJN award winning *Community as Partner* text Focusing on public health promotion practices in Canada this text examines the contemporary public health nurse's role as a hands on caregiver community detective and epidemiologist Part One provides a Canadian perspective on community nursing practice and legal ethical and sociocultural considerations Part Two presents the *Community as Partner* Model and Part Three contains case studies with Canadian examples This edition places more emphasis on supportive environments for health the five strategies of the Ottawa Charter primary health care and rural communities

**Prenatal Medicine** John M. G. van Vugt, Lee P. Shulman, 2016-04-19 At the cutting edge of maternal and neonatal management and research this reference presents the most recent advances in fetal DNA RNA embryoscopy fetoscopy open fetal surgery and ethnic population screening to manage pre existing and newly detected maternal medical complications detect genetic and congenital abnormalities prevent preterm bir

**Current Issues in Health Economics** Daniel Slottje, Rusty Tchernis, 2010-12-15 Presents research on some of



these key issues such as the impact of obesity on health children's healthcare policies education and health and many more

**New Ethics for the Public's Health** Dan E. Beauchamp, Bonnie Steinbock, 1999-07-29 Most books about ethics and health focus on issues arising from individual patients and their relationships with doctors and other health professionals. More and more however ethical issues are challenges that face entire communities not just individual patients. This book is an edited collection of readings that addresses these public health challenges. Many of the issues considered such as policy for alcohol and other drugs, newly emergent epidemics and violence prevention are public health concerns beyond the purview of traditional bioethics. Others such as access to health care, managed care, reproductive technologies and genetic testing are covered in bioethics texts but here they are approached from the distinct viewpoint of public health. The book makes explicit the community perspective of public health as well as the field's emphasis on prevention. It examines the conceptual issues raised by the public health perspective i.e. what is meant by community, the common good and individual autonomy as well as the policies that can be developed when health problems are approached in population based preventive terms.

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





















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