



Ethics And Research With Children A Case Based Approach

**Andrew E. Mulberg, Steven A.
Silber, John N. van den Anker**



Ethics And Research With Children A Case Based Approach:

Ethics and Research with Children Eric Kodish, Robert M. Nelson, 2018-11-26 Fundamental questions about the morality of pediatric medical research persist despite years of debate and the establishment of strict codes of ethics Is it ever permissible to use a child as a means to an end How much authority should parents have over decisions about research involving their children Should children or their parents be paid for participation in research Most importantly how can the twin goals of access to the benefits of clinical research and protection from research risk be reconciled Promoting more thoughtful attention to the complex ethical problems that arise when research involves children this fully updated new edition of *Ethics and Research with Children* presents 14 case studies featuring some of the most challenging and fascinating ethical dilemmas in pediatric research Each chapter begins with a unique case vignette followed by rich discussion and incisive ethical analysis Chapters represent a host of current controversies and are contributed by leading scholars from a variety of disciplines that must grapple with how to best protect children from research risk while driving innovation in the fight against childhood diseases Chapters end with questions for discussion providing faculty and students with accessible starting points from which to explore more in depth the thorny issues that are raised In the final chapter the editors provide a synthesis and summary that serve as a capstone and companion to the case based chapters Unique in its specific focus on research *Ethics and Research with Children* provides a balanced and thorough account of the enduring dilemmas that arise when children become research subjects and will be essential reading for those involved with pediatric research in any context

Ethics and Research with Children Eric Kodish, Robert M. Nelson, 2018-11-26 Promoting more thoughtful attention to the complex ethical problems that arise when research involves children this fully updated new edition of *Ethics and Research with Children* presents 14 case studies featuring some of the most challenging and fascinating ethical dilemmas in pediatric research

Handbook of Pediatric Psychology, Fifth Edition Michael C. Roberts, Ric G. Steele, 2018-03-21 Thousands of practitioners and students have relied on this handbook now thoroughly revised for authoritative information on the links between psychological and medical issues from infancy through adolescence Sponsored by the Society of Pediatric Psychology the volume explores psychosocial aspects of specific medical problems as well as issues in managing developmental and behavioral concerns that are frequently seen in pediatric settings The book describes best practices in training and service delivery and presents evidence based approaches to intervention with children and families All chapters have been rigorously peer reviewed by experts in the field New to This Edition Chapters on rural health the transition to adult medical care prevention and disorders of sex development Expanded coverage of epigenetics eHealth applications cultural and ethnic diversity spina bifida and epilepsy Many new authors extensively revised with the latest with the latest information on clinical populations research methods and interventions Chapters on training and professional competencies and quality improvement and cost effectiveness and international collaborations See also *Clinical Practice of*

Pediatric Psychology edited by Michael C Roberts Brandon S Aylward and Yelena P Wu which uses rich case material to illustrate intervention techniques Responsible Conduct of Research Adil E. Shamoo, David B. Resnik, 2009-02-12 Recent scandals and controversies such as data fabrication in federally funded science data manipulation and distortion in private industry and human embryonic stem cell research illustrate the importance of ethics in science Responsible Conduct of Research now in a completely updated second edition provides an introduction to the social ethical and legal issues facing scientists today **Pediatric Drug Development** Andrew E. Mulberg, Steven A. Silber, John N. van den Anker, 2011-09-20 Pediatric Drug Development Concepts and Applications is designed as a reference and textbook and is meant to address the science of differences between the pediatric and adult subject in the development of pharmaceutical products Considered are the ethics and medical needs of proper understanding the pediatric and adult differences the business case for proper development of drugs for children as well as the technical feasibility studies and processes that are necessary for a proper pediatric drug development program The applications of these approaches will benefit all stakeholders and ultimately not only educate but also provide better and safer drugs for pediatric patients **Handbook of Pediatric Psychology, Fourth Edition** Michael C. Roberts, Ric G. Steele, 2009-08-10 Sponsored by the Society of Pediatric Psychology this authoritative work is recognized as the definitive reference in the field In concise peer reviewed chapters leading authorities comprehensively examine links between psychological and medical issues from infancy through adolescence Psychosocial aspects of specific medical problems and developmental emotional and behavioral disorders are explored in depth The volume discusses issues in training and service delivery and reviews evidence based approaches to intervention and prevention See also Clinical Practice of Pediatric Psychology edited by Michael C Roberts Brandon S Aylward and Yelena P Wu which uses rich case material to illustrate intervention techniques The ^ADrama of DNA Karen H. Rothenberg JD, MPA, Lynn Wein Bush PhD, MS, MA, 2014-03-14 Through the use of dramatic narratives The Drama of DNA brings to life the complexities raised by the application of genomic technologies to health care and diagnosis This creative pedagogical approach shines a unique light on the ethical psychosocial and policy challenges that emerge as comprehensive sequencing of the human genome transitions from research to clinical medicine Narrative genomics aims to enhance understanding of how we evaluate process and share genomic information and to cultivate a deeper appreciation for difficult decisions encountered by health care professionals bioethicists families and society as this technology reaches the bedside

Proposed Revisions to the Common Rule for the Protection of Human Subjects in the Behavioral and Social Sciences National Research Council, Division of Behavioral and Social Sciences and Education, Committee on Population, Committee on National Statistics, Board on Behavioral, Cognitive, and Sensory Sciences, Committee on Revisions to the Common Rule for the Protection of Human Subjects in Research in the Behavioral and Social Sciences, 2014-03-31 Proposed Revisions to the Common Rule for the Protection of Human Subjects in the Behavioral and Social Sciences

examines how to update human subjects protections regulations so that they effectively respond to current research contexts and methods With a specific focus on social and behavioral sciences this consensus report aims to address the dramatic alterations in the research landscapes that institutional review boards IRBs have come to inhabit during the past 40 years The report aims to balance respect for the individual persons whose consent to participate makes research possible and respect for the social benefits that productive research communities make possible The ethics of human subjects research has captured scientific and regulatory attention for half a century To keep abreast of the universe of changes that factor into the ethical conduct of research today the Department of Health and Human Services published an Advance Notice of Proposed Rulemaking ANPRM in July 2011 Recognizing that widespread technological and societal transformations have occurred in the contexts for and conduct of human research since the passage of the National Research Act of 1974 the ANPRM revisits the regulations mandated by the Act in a correspondingly comprehensive manner Its proposals aim to modernize the Common Rule and to improve the efficiency of the work conducted under its auspices Proposed Revisions to the Common Rule for the Protection of Human Subjects in the Behavioral and Social Sciences identifies issues raised in the ANPRM that are critical and feasible for the federal government to address for the protection of participants and for the advancement of the social and behavioral sciences For each identified issue this report provides guidance for IRBs on techniques to address it with specific examples and best practice models to illustrate how the techniques would be applied to different behavioral and social sciences research procedures

Principles of Research in Behavioral Science Bernard

E. Whitley, Mary E. Kite, Heather L. Adams, 2013 Intended for beginning graduate or advanced undergraduate students this book provides a comprehensive review of research methods used in psychology and related disciplines It covers topics that are often omitted in other texts including correlational and qualitative research and integrative literature reviews Basic principles are reviewed for those who need a refresher The focus is on conceptual issues statistics are kept to a minimum Featuring examples from all fields of psychology the book addresses laboratory and field research Chapters are written to be used independently so instructors can pick and choose those that fit their course needs Reorganized to parallel the steps of the research process tips on writing reports are also provided Each chapter features an outline key terms a summary and questions and exercises that integrate chapter topics and put theory into practice A glossary and an annotated list of readings are now included Extensively updated throughout the new edition features a new co author Mary Kite and New chapters on qualitative research and content analysis and another on integrative literature reviews including meta analysis critical techniques for today's research environment A new chapter on exploratory and confirmatory factor analysis that addresses the use of path analysis and structural equation modeling A new chapter on how to write a research report using APA style Examples from cross cultural and multi cultural research neuroscience cognitive and developmental psychology along with ones from social industrial and clinical psychology More on Internet research and studies Greatly expanded Part 3

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Institutional Review Board: Management and Function Public Responsibility in Medicine & Research (PRIM&R), Elizabeth A. Bankert, Bruce G. Gordon, Elisa A. Hurley, 2021-03-01 Institutional Review Board IRB members and oversight personnel face challenges with research involving new technology management of big data globalization of research and more complex federal regulations Institutional Review Board Management and Function Third Edition provides everything IRBs and administrators need to know about efficiently managing and effectively operating a modern and compliant system of protecting human research subjects This trusted reference manual has been extensively updated to reflect the 2018 revisions to the Federal Policy for the Protection of Human Subjects Common Rule An essential resource for both seasoned and novice IRB administrators and members Institutional Review Board Management and Function provides comprehensive and understandable interpretations of the regulations clear descriptions of the ethical principles on which the regulations are based and practical step by step guidance for effectively implementing regulatory oversight

The Hereditary Basis of Childhood Cancer David Malkin, 2021-09-06 This volume elaborates on the research and clinical implications of the hereditary and molecular basis of childhood cancers The focus of the disease related chapters of the book is to integrate what is known about the molecular basis of that particular clinical entity or group of related entities with the clinical manifestations to relate the relationship of the molecular oncologic pathways with relevant developmental or non human species biology in order to better understand the complexity of these systems The resulting clinical implications of understanding this biology are elaborated on Chapters 13 16 discuss the broader psychosocial ethical and genetic counseling issues that arise and that are so critical to translating the knowledge gained from advances in molecular genetics into the clinic Chapter 12 in particular provides a unique perspective of the application of this knowledge in less developed nations where modern technologies may not be readily available but where the clinical manifestations of these disorders are prevalent

Handbook of Genomics and the Family Kenneth P. Tercyak, 2010-08-12 This book introduces readers to the study of how genes singly and in combination with each other and the environment affect health and behavior It provides family focused perspectives relating to genetic counseling and education

Clinical Ethics in Pediatrics Douglas S. Diekema, Mark R. Mercurio, Mary B. Adam, 2011-09-08 This volume provides a practical overview of the ethical issues arising in pediatric practice The case based approach grounds

the bioethical concepts in real life situations covering a broad range of important and controversial topics including informed consent confidentiality truthfulness and fidelity ethical issues relating to perinatology and neonatology end of life issues new technologies and problems of justice and public health in pediatrics A dedicated section also addresses the topics of professionalism including boundary issues conflicts of interests and relationships with industry ethical issues arising during training and dealing with the impaired or unethical colleague Each chapter contains a summary of the key issues covered and recommendations for approaching similar situations in other contexts Clinical Ethics in Pediatrics A Case Based Textbook is an essential resource for all physicians who care for children as well as medical educators residents and scholars in clinical bioethics

Nelson Textbook of Pediatrics E-Book Robert M. Kliegman, Bonita F. Stanton, Joseph St. Geme, Nina F. Schor, 2015-04-17 After more than 75 years Nelson Textbook of Pediatrics remains your indispensable source for definitive state of the art answers on every aspect of pediatric care Embracing the new advances in science as well as the time honored art of pediatric practice this classic reference provides the essential information that practitioners and other care providers involved in pediatric health care throughout the world need to understand to effectively address the enormous range of biologic psychologic and social problems that our children and youth may face Brand new chapters and comprehensive revisions throughout ensure that you have the most recent information on diagnosis and treatment of pediatric diseases based on the latest recommendations and methodologies Form a definitive diagnosis and create the best treatment plans possible using evidence based medicine and astute clinical experiences from leading international authors many new to this edition A NEW layout provides superior portability and exceptional ease of use Gain a more complete perspective Along with a broader emphasis on imaging and molecular diagnoses and updated references the new edition includes an increased focus on international issues to ensure relevance in pediatrics practice throughout the world Effectively apply the latest techniques and approaches with complete updates throughout 35 new chapters including Innovations in Addressing Child Health and Survival in Low Income Settings Developmental Domains and Theories of Cognition The Reggio Emilia Educational Approach Catatonia Refeeding Syndrome Altitude associated Illness Genetic Approaches to Rare and Undiagnosed Diseases Healthcare Associated Infections Intrapartum and Peripartum Infections Bath salts and other drugs of abuse Small Fiber Polyneuropathy Microbiome *Kingella kingae* Mitochondrial Neurogastrointestinal Encephalomyopathy Nonalcoholic Fatty Liver Disease Plagiocephaly CNS Vasculitis Anterior Cruciate Ligament Rupture and Sports Related Traumatic Brain Injury Recognize diagnose and manage genetic and acquired conditions more effectively A new Rehabilitation section with 10 new chapters including Evaluation of the Child for Rehabilitative Services Severe Traumatic Brain Injury Spinal Cord Injury and Autonomic Crisis Management Spasticity Birth Brachial Plexus Palsy Traumatic and Sports Related Injuries Meningocele Health and Wellness for Children with Disabilities Manage the transition to adult healthcare for children with chronic diseases through discussions of the overall health needs of patients

with congenital heart defects diabetes and cystic fibrosis Understand the principles of therapy and which drugs and dosages to prescribe for every disease

The SAGE Encyclopedia of Research Design Bruce B. Frey, 2022-01-27 The SAGE Encyclopedia of Research Design maps out how one makes decisions about research design interprets data and draws valid inferences undertakes research projects in an ethical manner and evaluates experimental design strategies and results From A to Z this four volume work covers the spectrum of research design strategies and topics including among other things fundamental research design principles ethics in the research process quantitative versus qualitative and mixed method designs completely randomized designs multiple comparison tests diagnosing agreement between data and models fundamental assumptions in analysis of variance factorial treatment designs complete and incomplete block designs Latin square and related designs hierarchical designs response surface designs split plot designs repeated measures designs crossover designs analysis of covariance statistical software packages and much more Research design with its statistical underpinnings can be especially daunting for students and novice researchers At its heart research design might be described simply as a formalized approach toward problem solving thinking and acquiring knowledge the success of which depends upon clearly defined objectives and appropriate choice of statistical design and analysis to meet those objectives The SAGE Encyclopedia of Research Design will assist students and researchers with their work while providing vital information on research strategies

Pediatric Biomedical Informatics John J. Hutton, 2012-12-13 Advances in the biomedical sciences especially genomics proteomics and metabolomics taken together with the expanding use of electronic health records are radically changing the IT infrastructure and software applications needed to support the transfer of knowledge from bench to bedside Pediatric Biomedical Informatics Computer Applications in Pediatric Research describes the core resources in informatics necessary to support biomedical research programs and how these can best be integrated with hospital systems to receive clinical information that is necessary to conduct translational research The focus is on the authors recent practical experiences in establishing an informatics infrastructure in a large research intensive children s hospital This book is intended for translational researchers and informaticians in pediatrics but can also serve as a guide to all institutions facing the challenges of developing and strengthening informatics support for biomedical research The first section of the book discusses important technical challenges underlying computer based pediatric research while subsequent sections discuss informatics applications that support biobanking and a broad range of research programs Pediatric Biomedical Informatics provides practical insights into the design implementation and utilization of informatics infrastructures to optimize care and research to benefit children Dr John Hutton is the Vice President and Director of Biomedical Informatics at Cincinnati Children s Hospital Medical Center Cincinnati OH USA He is also Professor of Pediatrics and Associate Dean for Information Services at the University of Cincinnati College of Medicine

Opioids in Cancer Pain Mellor P. Davis, 2009-05-28 Opioids can be effective in relieving pain in more than 90% of cancer patients However often

irrational fears from both patients and clinicians persist about the potential for addiction meaning treatable pain continues to be tolerated This book offers clear guidelines on the use of opioids when managing cancer pain **Encyclopedia of**

Research Design Neil J. Salkind, 2010-06-22 To request a free 30 day online trial to this product visit www.sagepub.com/freetrial Research design can be daunting for all types of researchers At its heart it might be described as a formalized approach toward problem solving thinking and acquiring knowledge the success of which depends upon clearly defined objectives and appropriate choice of statistical tools tests and analysis to meet a project s objectives Comprising more than 500 entries the Encyclopedia of Research Design explains how to make decisions about research design undertake research projects in an ethical manner interpret and draw valid inferences from data and evaluate experiment design strategies and results Two additional features carry this encyclopedia far above other works in the field bibliographic entries devoted to significant articles in the history of research design and reviews of contemporary tools such as software and statistical procedures used to analyze results Key Features Covers the spectrum of research design strategies from material presented in introductory classes to topics necessary in graduate research Addresses cross and multidisciplinary research needs with many examples drawn from the social and behavioral sciences neurosciences and biomedical and life sciences Provides summaries of advantages and disadvantages of often used strategies Uses hundreds of sample tables figures and equations based on real life cases Key Themes Descriptive Statistics Distributions Graphical Displays of Data Hypothesis Testing Important Publications Inferential Statistics Item Response Theory Mathematical Concepts Measurement Concepts Organizations Publishing Qualitative Research Reliability of Scores Research Design Concepts Research Designs Research Ethics Research Process Research Validity Issues Sampling Scaling Software Applications Statistical Assumptions Statistical Concepts Statistical Procedures Statistical Tests Theories Laws and Principles Types of Variables Validity of Scores The Encyclopedia of Research Design is the perfect instrument for new learners as well as experienced researchers to explore both the original and newest branches of the field **Conflicts in Conservation** Stephen M. Redpath, R. J. Gutiérrez, Kevin

A. Wood, Juliette C. Young, 2015-05-07 Conflicts over the conservation of biodiversity are increasing and are serious obstacles to wildlife conservation efforts worldwide Changing patterns in land use over exploitation pollution climate change and the threat posed by invasive species all challenge the way we currently maintain and protect biodiversity from the local management of single species to the international management of resources Integrating approaches from different academic disciplines policy makers and practitioners this volume offers a radically new cross disciplinary multi scale approach to deal with conflicts Groundbreaking strategies for conservation are analysed and a large section of the book is devoted to exploring case studies of conflict from around the world Aimed primarily at academics researchers and students from disciplines relating to conservation ecology natural resources management and environmental governance this book will be equally valuable to conservation NGOs and practitioners and the policy community at national and international levels

Designing and Conducting Research in Education Clifford J. Drew, Michael L. Hardman, John L. Hosp, 2008 The research process in this book begins with identification of the research question and proceeds through each step including planning data collection actual collection and analysis of the data and writing the report This text proceeds through multiple methodologies including experimental and non experimental quantitative and qualitative At every step the emphasis is on planning and executing the study Key features o Simulations and feedback that may be used in class sessions for both individual and small group participation o Pedagogy to help students plan and conduct a research project in an actual classroom o Examples that demonstrate and explain what constitutes good and poor research questions o Case studies and real life examples related to education o A Student Web site that provides students with the opportunity to interact with contemporary articles This book provides an introduction to research that emphasizes the fundamental concepts of planning and design It is designed to be a core text for the very first course on research methods

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