CONTENTS

| FOREWO | RD: Why Bother with Ethics in Biomedical Research? | |
|---------|---|--|
| | ALEXANDER MORGAN CAPRON | xi |
| PREFACE | 3 | xiii |
| Introdu | INTRODUCTION: Development, Research, and Vulnerability | |
| | Matti Häyry, Tuija Takala, and Peter Herissone-Kelly | |
| | The Internationality of Research Ethics Facts, Fears, and Hopes Concerning Development Research and Technology as Answers and as Questions Vulnerability, Power, and Responsibility The Role of International Bioethics | 1 1 3 4 6 |
| | Part One: | |
| | FACTS, FEARS, AND HOPES CONCERNING DEVELOPMENT | 7 |
| One | New Perspectives on International Research Ethics SOLOMON R. BENATAR | 9 |
| | Themes and Background Trends in International Collaborative Clinical Research Why Do We Persist with the Current Emphasis? HIV/AIDS and the Recrudescence of Infectious Diseases Persisting Controversies in International Clinical Research Standard of Care Making Progress through New Perspectives Conclusion | 9 10 11 13 14 15 17 18 |
| Two | Some Current Issues in the Ethics of Biomedical Research and Their Background in the Protection of the Dignity and Autonomy of the Vulnerable MATTI HÄYRY | 21 |
| | Themes and Background Bioethics: Its Scope and Approaches Dignity and Autonomy of the Vulnerable The First Phase of Bioethics The Second Phase of Bioethics Dignity, Autonomy, and Stem Cell Research Political Rhetoric and Genetically Altered Food Products Justice, Solidarity, and Pharmaceutical Research The Paradox of Trust Construction by Destruction | 21 22 23 24 25 26 28 29 29 30 |

| E Bioethics and Biomedicine: Developing Countries' Perspective | |
|---|---|
| Florencia Luna | |
| Introduction Causes of Illness and Mortality in Developing Countries Biomedicine Today Biomedicine Research in Developing Countries Conclusion | 33 33 35 39 43 |
| Brazilian Research Ethics: A North-South Dialogue Aiming to Build a New Culture of Respect | 47 |
| LEO PESSINI AND LEONARD M. MARTIN | |
| Introduction The Emergence of Brazilian Research Ethics International Declarations, Documents, and Standards The Brazilian Contribution to the Discussion Conclusion | 47 47 50 51 53 |
| Who Sets the Agenda for Health Research in Developing Countries? A Call for More Community Involvement ANGELA AMONDI WASUNNA | 57 |
| Health Research in Developing Countries Categories of Health Research Research Responsive to Community Health Needs Research on Needs within Community Priorities Research on Needs Outside Community Priorities Revisiting the Three Categories of Research | 57 57 58 59 62 63 |
| Part Two: Research and Technology as Answers and as Ouestions | 67 |
| Ethical Aspects in Introducing Genetically Modified Organisms for Public Health Purposes DARRYL MACER | 69 |
| 1. Introduction | 69 |
| 2. The Ethics of Disease Prevention | 69 |
| 3. Bioethics and Molecular Entomology | 71 |
| | 73 |
| | 74 |
| | 74 76 |
| | 76 77 |
| | 79 |
| 10. Conclusion | 81 |
| E | Perspective FLORENCIA LUNA 1. Introduction 2. Causes of Illness and Mortality in Developing Countries 3. Biomedicine Today 4. Biomedicine Research in Developing Countries 5. Conclusion Brazilian Research Ethics: A North-South Dialogue Aiming to Build a New Culture of Respect LEO PESSINI AND LEONARD M. MARTIN 1. Introduction 2. The Emergence of Brazilian Research Ethics 3. International Declarations, Documents, and Standards 4. The Brazilian Contribution to the Discussion 5. Conclusion Who Sets the Agenda for Health Research in Developing Countries? A Call for More Community Involvement ANGELA AMONDI WASUNNA 1. Health Research in Developing Countries 2. Categories of Health Research 3. Research on Needs within Community Priorities 5. Research on Needs Outside Community Priorities 6. Revisiting the Three Categories of Research Part Two: RESEARCH AND TECHNOLOGY AS ANSWERS AND AS QUESTIONS Ethical Aspects in Introducing Genetically Modified Organisms for Public Health Purposes DARRYL MACER 1. Introduction 2. The Ethics of Disease Prevention 3. Bioethics and Molecular Entomology 4. Intrinsic Ethical Issues of Genetic Engineering 5. Animal Rights Concerns 6. Consent from Trial Participants 7. Duties to the Community in Environmental Manipulation 8. Envisio of Technology Choices |

| SEVEN | The Ethical Review of Research into Rare Genetic Disorders | 87 |
|-------|---|------------|
| | MICHAEL PARKER, RICHARD ASHCROFT, ANDREW WILKIE, AND ALASTAIR KENT | |
| | 1. Rare Cases | 87 |
| | 2. The Problem | 88 |
| | 3. Research and Clinical Practice | 89 |
| | Review of Research into Rare Conditions Conclusion | 91 94 |
| Eight | Ongoing and Emerging Biomedical Research Issues at | |
| | the Beginning of Life: United States Perspectives ROSEMARIE TONG | 97 |
| | 1. Introduction | 97 |
| | 2. Biomedical Research on Fetuses, Embryos, Pre-Embryos | 98 |
| | 3. Therapeutic Cloning in the United States | 100 |
| | 4. Reproductive Cloning in the United States | 104 |
| | The Value of Life and Ectogenesis in the United States Conclusion | 107 109 |
| NINE | Human Stem Cell Research as a Promising Hope for | |
| | Humankind: A Christian-Ethical Contribution | 113 |
| | BART HANSEN AND PAUL SCHOTSMANS | |
| | 1. Introduction | 113 |
| | 2. A Terminological Clarification | 113 |
| | 3. Societal Reactions | 114 |
| | The Debate on the Moral Status of the Human Embryo Human beings as Created Co-Creators | 117 118 |
| | 6. Conclusion | 121 |
| Ten | Interrelations between Bioethics and Ethics of Bio- | |
| | technology | 125 |
| | Boris G. Yudin | |
| | 1. Two Fields of Ethical Concern | 125 |
| | 2. Internal and External Considerations | 127 |
| | 3. Preservation and Safety | 129 |
| | 4. Changes and Hope | 130 |

Contents

vii

Contents

| | Part Three: VULNERABILITY, POWER, AND RESPONSIBILITY | 133 |
|----------|--|--|
| Eleven | Infectious Disease and the Ethics of Research: The Moral Significance of Communicability LESLIE P. FRANCIS, MARGARET P. BATTIN, JEFFREY R. BOTKIN, JAY A. JACOBSON, AND CHARLES B. SMITH | 135 |
| | Risks to Indirect Participants Current Informed Consent Policies and Contagiousness Historical Examples of Ignoring Contagion Historical Examples of Considering Contagion Contemporary Examples of Ignoring Contagion Considering the Risks to Indirect Participants Considering Indirect Participants: How Far to Go? | 135 136 138 140 142 144 146 |
| TWELVE | Is There a Duty to Serve as Research Subjects? LEONARDO D. DE CASTRO | 151 |
| | Two Forms of the Question Why Ask the Question? Medical Duty and Political Obligation Medical Benefits Model The Fairness Model Harm Prevention Model Responsibility and Reciprocity to Future Generations Derivation of Duty to Serve as Research Subjects The Urgency of Research Duty and Responsibility | 151 152 154 155 156 157 158 159 162 164 |
| THIRTEEN | Vulnerability in Biomedical Research: A Framework for Analysis ELMA LOURDES CAMPOS PAVONE ZOBOLI | 167 |
| | Introduction Vulnerability and AIDS Vulnerability and Biomedical Research Ethics A Vulnerability Analysis Framework Conclusion | 167 168 170 173 179 |
| Fourteen | New Vulnerabilities Raised by Biomedical Research MARIA PATRÃO DO CÉU NEVES | 181 |
| | Introduction Ethical Reflection Part of Experimentation Vulnerability in Human Experimentation "Ethic of Rights" and Vindication of an "Ethics of Duty" | 181 181 185 191 |

| Contents | , |
|----------|---|
|----------|---|

| Fifteen | How to Save the World: Some Alternatives to Bio- medical Research FRANK J. LEAVITT | 193 |
|----------|--|-----------|
| | FRANK J. LEAVIII | |
| | 1. Introduction: A Pound of Prevention or an Ounce of | Cure? 193 |
| | 2. Education for Disease Prevention | 195 |
| | 3. The Kitchen Garden Model | 197 |
| | 4. Individual Health Autonomy | 200 |
| | 5. Methodological Difficulties | 204 |
| | 6. Conclusion: Anecdote, the Mother of Science | 207 |
| ABOUT TH | E AUTHORS | 213 |
| INDEX | | 221 |

ix