

# **INTRODUCTION**



# INTRODUCTION

## The Field of Bioethics

Bioethics can be defined as the systematic study of value questions that arise in health care delivery and in biomedicine. Specific bioethical issues that have recently received national and international attention include euthanasia, assisted suicide, new reproductive technologies, cloning, human experimentation, genetic engineering, the neurosciences, abortion, informed consent, acquired immunodeficiency syndrome (AIDS), organ donation and transplantation, and managed care and other concerns in the allocation of health care resources.

As this list of topics suggests, the field of bioethics includes several dimensions. The first is the ethics of the professional patient relationship. Traditionally, the accent has been on the duties of health professionals—duties that, since the time of Hippocrates, have frequently been delineated in codes of professional ethics. In more recent times the rights of patients have also received considerable attention. Research ethics, the study of value problems in biomedical and behavioral research, constitutes a second dimension of bioethics. During the 20<sup>th</sup> century and the start of the 21<sup>st</sup> century, as both the volume and visible achievements of such research have increased, new questions have arisen concerning the investigator-subject relationship and the potential social impact of biomedical and behavioral research and technology. In recent years a third dimension of bioethics has emerged—the quest to develop reasonable public policy guidelines for both the delivery of health care and the allocation of health care resources, as well as for the conduct of research.

No single academic discipline is adequate to discuss these various dimensions of bioethics. For this reason bioethics has been, since its inception in the late 1960s, a cross-disciplinary field. The primary participants in the interdisciplinary discussion have been physicians and other health professionals, biologists, psychologists, sociologists, lawyers, historians, and philosophical and religious ethicists.

During the past thirty-five years there has been a rapid growth of academic, professional, and public interest in the field of bioethics. One evidence of this interest is the establishment of numerous research institutes and teaching programs in bioethics, both in the United States and abroad. Professional societies, federal and state legislatures, and the courts have also turned increasing attention to problems in the field. In addition, there has been a veritable explosion of literature on bioethical issues.

The literature of bioethics appears in widely scattered sources and is reported in diverse indexes which employ a bewildering variety of subject headings. This annual *Bibliography* is the product of a unique information retrieval system designed to identify the central issues of bioethics, to develop a subject classification scheme appropriate to the field, and to provide comprehensive, cross-disciplinary coverage of current English-language materials on bioethical topics.

Volume 35 of the *Bibliography* contains one year's worth of the literature garnered by this comprehensive information system. Specifically, it includes selected citations that were acquired in 2008 by two projects at the Kennedy Institute of Ethics: the National Reference Center for Bioethics Literature (NRCBL) and the National Information Resource on Ethics & Human Genetics (NIREHG).

The Table of Contents includes a list of subject headings used to arrange the citations. Most citations are listed once, under their primary subject heading. Classification numbers at the end of each citation represent additional topics covered by the publication. These classification numbers are drawn from the NRCBL's Classification Scheme, reproduced on the inside front cover. The inside back cover offers a key to going from brief citations in Section II to more complete citations in Section I.

# BIBLIOGRAPHY OF BIOETHICS

## The Scope of the Bibliography

This thirty-fifth volume of the *Bibliography of Bioethics* includes materials which discuss the ethical aspects of the following major topics and subtopics:

### BIOETHICS, MEDICAL ETHICS, AND PROFESSIONAL ETHICS

- Codes of Ethics
- Commissions
- Education
- Ethicists and Ethics Committees
- History
- Professional Ethics
- Professional Ethics in Medicine
- Professional Ethics in Nursing
- Quality and Value of Life

### DEATH AND DYING

- Advance Directives
- Assisted Suicide
- Attitudes to Death
- Capital Punishment
- Determination of Death
- Euthanasia and Allowing to Die
- Terminal Care

### GENETICS AND GENOMICS

- Behavioral Genetics
- Chimeras and Hybrids
- DNA Fingerprinting
- Eugenics
- Forensic Genetics
- Gene Therapy
- Genetic Counseling
- Genetic Databases and Biobanks
- Genetic Engineering and Biotechnology
- Genetic Enhancement
- Genetic Privacy
- Genetic Research
- Genetic Screening
- Genetically Modified Organisms and Food
- Genetics and Human Ancestry
- Genome Mapping and Sequencing
- Nutrigenomics
- Patents
- Pharmacogenetics
- Synthetic Biology

### HEALTH CARE AND PUBLIC HEALTH

- AIDS
- Blood Banking, Donation and Transfusion
- Care for Specific Groups
- Drug Industry

- Health, Concept of
- Mental Health, Concept of
- Health Care
- Health Care Economics
- Health Care Quality
- Occupational Health
- Organ and Tissue Transplantation
- Resource Allocation
- Right to Health Care
- Sexuality
- Telemedicine and Informatics

### MENTAL HEALTH THERAPIES AND NEUROSCIENCES

- Behavior Control
- Electroconvulsive Therapy
- Involuntary Commitment
- Psychopharmacology
- Psychosurgery
- Psychotherapy

### PATIENT RELATIONSHIPS

- Confidentiality
- Informed Consent
- Treatment Refusal
- Truth Disclosure

### REPRODUCTION AND REPRODUCTIVE TECHNOLOGIES

- Abortion
- Artificial Insemination and Surrogate Mothers
- Cloning
- Contraception
- Cryobanking of Sperm, Ova, and Embryos
- In Vitro Fertilization
- Sex Determination and Selection
- Sterilization

### RESEARCH

- Animal Experimentation
- Behavioral Research
- Biomedical Research
- Enhancement Technologies
- Human Experimentation
- Nanotechnology
- Research Ethics and Scientific Misconduct
- Social Control of Science and Technology
- Stem Cell Research and Transplantation

## INTRODUCTION

### SOCIOLOGY OF MEDICINE

Cultural Pluralism  
Journalism and Publishing  
Malpractice and Professional Misconduct  
Medical and Health Professional Education  
Professional Relationships

### WAR AND HUMAN RIGHTS ABUSES

International Health and Human Rights  
International Migration of Health Care Professionals  
Torture, Genocide, and War Crimes  
War and Terrorism

This volume of the *Bibliography* cites 8,195 documents (primarily in English) that discuss ethical and related public policy aspects of the topics and subtopics listed above. Documents cited in this volume include journal and newspaper articles, laws, court decisions, monographs, and chapters in books. Most of the documents listed were published since 2006. In the *Periodical Literature and Essays* section, for example, 4,229 of the 7,454 entries were published in 2008; 2,162 in 2007; and 676 in 2006; therefore, 95 per cent of the literature cited in Section I was published from 2006 to 2008.

A cross-disciplinary monitoring system has been devised in an effort to secure documents falling within the subject-matter scope outlined above. Among the reference tools and databases searched for pertinent citations are the following:

Choice	NLM Catalog
Current Contents: Social and Behavioral Sciences	PUBMED
Dissertations and Theses (UMI Proquest)	Specialty Law Digest: Health Care
ERIC	Tarlton Law Library Legal Bibliography Series
Library Journal	WorldCat
New Titles in Bioethics	

In addition, the *Bibliography* staff directly monitors hundreds of web sites on an ongoing basis as well as 179 journals and newspapers for articles falling within the scope of bioethics. Those preceded by an asterisk (\*) have given permission for abstracts to be included in this volume. It is important to note that the journal articles cited in this volume are actually drawn from many more journals than those listed below.

Academic Medicine	Cerebrum
*Accountability in Research	*Christian Bioethics
Agriculture and Human Values	Christian Century
AIDS and Public Policy Journal	Clinical Ethics
America	Community Genetics
*American Journal of Bioethics	DePaul Journal of Health Care Law
*American Journal of Law and Medicine	Developing World Bioethics
American Journal of Nursing	Dolentium Hominum
American Journal of Psychiatry	Environmental Ethics
*American Journal of Public Health	Ethical Human Psychology and Psychiatry
Annals of Health Law	Ethical Perspectives
*Annals of Internal Medicine	Ethical Theory and Moral Practice
APA Newsletter on Philosophy and Medicine	*Ethics
*Archives of Internal Medicine	*Ethics and Behavior
ATLA: Alternatives to Laboratory Animals	Ethics and Intellectual Disability
*Bioethics	Ethics and Medicine
Bioethics Forum	Ethics and Medics
BMC Medical Ethics [electronic resource]	*Eubios Journal of Asian and International Bioethics
*BMJ (British Medical Journal)	European Journal of Health Law
British Journal of Nursing	First Things: A Monthly Journal of Religion and Public Life
*Cambridge Quarterly of Healthcare Ethics	Formosan Journal of Medical Humanities
Canadian Medical Association Journal	Free Inquiry
CCAR Journal	Genetic Testing

## BIBLIOGRAPHY OF BIOETHICS

- Genetics in Medicine  
GeneWatch  
Georgetown Journal of Legal Ethics  
\*Hastings Center Report  
Health Affairs  
Health and Human Rights  
\*Health Care Analysis  
Health Care Ethics USA [online]  
Health Law in Canada  
Health Law Journal  
Health Law Review  
Health Matrix (Cleveland)  
Health Policy [ISSN 0168-8510]  
Health Progress  
\*HEC Forum  
Human Life Review  
Human Reproduction  
Human Reproduction and Genetic Ethics  
Human Research Report  
Humane Health Care [electronic resource]  
Hypatia  
IDHL: International Digest of Health Legislation [electronic resource]  
Indian Journal of Medical Ethics  
Indiana Health Law Review  
Intellectual and Developmental Disabilities  
International Journal of Applied Philosophy  
\*International Journal of Bioethics (Journal International de Bioéthique)  
International Journal of Health Services  
International Journal of Law and Psychiatry  
International Journal of Technology Assessment in Health Care  
IRB: Ethics and Human Research  
Issues in Law and Medicine  
Issues in Science and Technology  
\*JAMA  
Jewish Medical Ethics and Halacha  
JONA's Healthcare Law, Ethics, and Regulation  
Journal of Advanced Nursing  
Journal of Applied Animal Welfare Science  
Journal of Applied Philosophy  
\*Journal of Bioethical Inquiry  
Journal of Biolaw and Business  
\*Journal of Clinical Ethics  
Journal of Contemporary Health Law and Policy  
Journal of Ethics  
Journal of General Internal Medicine  
Journal of Genetic Counseling  
Journal of Halacha and Contemporary Society  
Journal of Health Care Law and Policy  
\*Journal of Health Politics, Policy and Law  
Journal of Information Ethics  
Journal of Intellectual Disability Research  
Journal of Law and Health  
Journal of Law and Religion  
\*Journal of Law, Medicine and Ethics  
Journal of Legal Medicine  
\*Journal of Medical Ethics  
Journal of Medical Genetics  
\*Journal of Medical Humanities  
\*Journal of Medicine and Philosophy  
Journal of Moral Education  
Journal of Nursing Law  
Journal of Palliative Care  
Journal of Philosophy, Science and Law  
Journal of Professional Nursing  
Journal of Psychiatry and Law  
Journal of Public Health Policy  
Journal of Religion and Health  
Journal of Religious Ethics  
Journal of Social Philosophy  
Journal of the American Academy of Psychiatry and the Law  
Journal of the American College of Dentists  
Journal of the American Geriatrics Society  
Judaism  
\*Kennedy Institute of Ethics Journal  
\*Lancet  
Law and the Human Genome Review (Revista de Derecho y Genoma Humano)  
Legal Medical Quarterly  
Linacre Quarterly  
Literature and Medicine  
Medical Ethics & Bioethics (Medicinska Etika & Bioetika)  
Medical Humanities  
Medical Humanities Review  
Medical Law International  
Medical Law Review  
Medicine and Law  
Medicine, Conflict and Survival  
Medicine, Health Care and Philosophy  
Mental Retardation [ISSN 0047-6765]  
\*Milbank Quarterly  
Minnesota Medicine  
Monash Bioethics Review  
NanoEthics  
\*National Catholic Bioethics Quarterly  
\*Nature  
Nature Biotechnology  
Nature Medicine  
NCEHR Communiqué (National Council on Ethics in Human Research)

New Atlantis	Public Affairs Quarterly
*New England Journal of Medicine	*Science
New Genetics and Society	Science and Engineering Ethics
New Scientist	Science as Culture
New York Times	Science, Technology, and Human Values
Newsweek	Sh'ma
Notizie de Politeia	Social Justice Research
Notre Dame Journal of Law, Ethics and Public Policy	Social Philosophy and Policy
*Nursing Ethics	Social Science and Medicine
Online Journal of Issues in Nursing	Social Theory and Practice
Origins	*Theoretical Medicine and Bioethics
Perspectives in Biology and Medicine	Tradition
Perspectives on the Professions: Ethical & Policy Issues	Update (Loma Linda University Ethics Center)
Pharos	U.S. News and World Report
*Philosophy and Public Affairs	Virtual Mentor: Ethics Journal of the American Medical Association [electronic resource]
Philosophy and Public Policy Quarterly	Washington Post
Politics and the Life Sciences	Women's Health Issues
Protecting Human Subjects	Yale Journal of Health Policy, Law, and Ethics
Psychiatric Services	

Many documents cited by the *Bibliography* are in the collection of the NRCBL.

### Arrangement of the *Bibliography*

This volume of the *Bibliography of Bioethics* is divided into five parts:

1. Introduction
2. Section I: Periodical Literature and Essays — Subject Entries
3. Section II: Periodical Literature and Essays — Author Index
4. Section III: Monographs — Subject Entries
5. Section IV: Monographs — Title Index.

Sections 2 and 4 constitute the core of the *Bibliography*.

#### Section 1: Periodical Literature and Essays — Subject Entries

This Section, one of the two main parts of the *Bibliography*, contains usually one entry for each of the documents selected by the bioethics information retrieval system during the preceding year. In Volume 35 of the *Bibliography*, entries for 7,454 documents have been included in the Section. The most commonly cited formats are journal articles (85%), book chapters (12%), and newspaper articles (2%).

Section I is organized under 86 major subject headings, of which 12 are further divided by subheadings. Each subheading is separated from the major subject term by a slash.

Readers of the *Bibliography* should first scan the alphabetic list of subject headings in the Table of Contents to determine where citations of interest to them are likely to be found.

Section I includes cross references of two types. *See* cross references lead the reader from terms that are not used as subject headings to terms that are used. *See also* cross references suggest additional subject headings where the reader may find citations of related interest.

Citations appear alphabetically by author, with anonymous citations at the beginning of the section, sorted alphabetically by title. Entries with both corporate and personal authors are sorted by the corporate author. As explained below, the citations are accompanied by NRCBL Classification Scheme numbers as well as, in some cases, Subject Captions denoting approach or content.

## BIBLIOGRAPHY OF BIOETHICS

Subject Caption definitions can be found on page footers. Abstracts are again included in this volume. Several optional fields provide additional information: identifiers (such as persons, places, organizations, acronym equivalents), conference information, comments regarding related publications, and general notes.

With the support of a grant from the U.S. National Human Genome Research Institute, bibliographers began indexing the genetics literature early in 2007 using the *Bioethics Thesaurus for Genetics* (see <http://bioethics.georgetown.edu/nirehg/index.htm>), a controlled vocabulary developed specifically for this project, using the *Bioethics Thesaurus*, originally developed for the BIOETHICSLINE database, as its foundation. The indexed citations are accompanied by keywords, proposed keywords, and keyword identifiers (usually proper nouns) in Section I. In addition to enhancing the representation of the content of each indexed citation, the keywords are used to generate more precise subject categories for the genetics literature. New subject headings appearing in this volume are: DNA FINGERPRINTING, FORENSIC GENETICS, NUTRIGENOMICS, and SYNTHETIC BIOLOGY.

Now eighteen data elements may appear in a citation. A sample subject heading and entry for a journal article follow:

### GENETIC DATABASES AND BIOBANKS <sup>1</sup>

**Murphy, Juli; Scott, Joan; Kaufman, David; Geller, Gail; LeRoy, Lisa; Hudson, Kathy.**<sup>2</sup> Public expectations for return of results from large-cohort genetic research.<sup>3</sup> *American Journal of Bioethics*<sup>4</sup> 2008 November<sup>5</sup>; 8(11)<sup>6</sup>: 36-43<sup>7</sup>. 44 refs.<sup>8</sup> NRCBL: 15.1; 18.3<sup>9</sup>. SC: em<sup>10</sup>. Comments: See comments in: *American Journal of Bioethics* 2008 November; 8(11): 44-50.<sup>14</sup>

Keywords: \*choice behavior; \*disclosure; \*duty to recontact; \*genetic databases; \*genetic research; \*public opinion; \*research findings; \*research subjects; access to information; adults; Alzheimer disease; clinical utility; costs and benefits; focus groups; genetic diversity; genetic predisposition; genetic privacy; genomics; incentives; moral obligations; public participation; qualitative research; risks and benefits; tissue donors; therapeutic misconception<sup>15</sup>; Proposed Keywords: asthma; cohort studies<sup>16</sup>; Keyword Identifiers: National Institutes of Health; United States<sup>17</sup>

Abstract: The National Institutes of Health and other federal health agencies are considering establishing a national biobank to study the roles of genes and environment in human health. . . .<sup>18</sup>

1. Subject heading: **GENETIC DATABASES AND BIOBANKS**
2. Author(s): **Murphy, Juli; Scott, Joan; Kaufman, David; Geller, Gail; LeRoy, Lisa; Hudson, Kathy.**
3. Title of article: Public expectations for return of results from large-cohort genetic research.
4. Title of journal: *American Journal of Bioethics*
5. Date of publication: 2008 November
6. Volume and issue number (if available): 8(11)
7. Pagination: 36-43
8. References: 44 refs. (optional)
9. NRCBL (all classification numbers): 15.1; 18.3
10. SC (Subject Captions): em [empirical] (optional)
11. Identifiers: (optional; not present here)
12. Note: additional information (optional; not present here)
13. Conference: (optional; not present here)
14. Comments: Comments: See comments in: *American Journal of Bioethics* 2008 November; 8(11): 44-50. (optional)
15. Keywords: \*choice behavior; \*disclosure; etc. (optional)
16. Proposed Keywords: asthma; cohort studies (optional)
17. Keyword Identifiers: National Institutes of Health; United States (optional)
18. Abstract: The National Institutes of Health and other federal health agencies. . . . (optional)

The journal article is the most prevalent publication type. The title field may be augmented by terms in square brackets which indicate additional aspects of the document, such as: letter, editorial, and news. The complete NRCBL Classification Scheme can be found on the inside front cover, and the Subject Captions equivalents are on alternating footers in Section I. The inside back cover displays the Subject Heading Key for Section II, leading the reader from the primary, i.e. first, NRCBL number to the corresponding Subject Heading(s) in Section I. Most citations appear only once in this volume.

### Section II: Periodical Literature and Essays — Author Index

Citations in the Author Index are followed by the primary NRCBL Classification Number (Subject). Citations that have no personal or corporate author are listed at the end of the Author Index for Periodical Literature and Essays under ANONYMOUS. The two-page SUBJECT HEADING KEY FOR SECTION II appears on the inside back cover; it provides subject heading equivalents in Section I for the subject numbers appearing at the end of each citation in Section II.

### Section III: Monographs — Subject Entries

These records have been derived from the annual publication of the NRCBL's *New Titles in Bioethics*, and cite monographs added to the collection in 2008 that cover bioethics and related areas of ethics and applied ethics. The NRCBL Classification Scheme (reproduced in full on the inside front cover) provides the arrangement for these citations. The Monographs section includes 741 records for books, reports, audiovisuals, special issues of journals, and new periodical subscriptions. Only subject headings actually occurring in Volume 35 are included on this list.

The monograph citations are arranged according to the primary subject category of the volume, and then, under subject category, by author, editor, producer, or title. Each citation in the Section usually appears only once. Classification numbers at the end of each citation represent additional bioethics topics covered by the publication. Monograph entries also include acquisition information, especially important for the so-called "gray literature." Monographs in foreign languages are included in the *Bibliography*.

### Section IV: Monographs — Title Index

This Section provides a title index to all the entries in the Monographs Section. The title is followed by the subject section and author within which the complete citation can be found.

## The *Bibliography of Bioethics*: History and Current Availability on the World Wide Web

Through December 2000, the entries in all of the annual volumes of the *Bibliography of Bioethics* were available online in BIOETHICSLINE, a database produced for the National Library of Medicine (NLM) by the Bioethics Information Retrieval Project at the Kennedy Institute of Ethics, Georgetown University. As of 2001, NLM incorporated its subject-oriented databases—including BIOETHICSLINE—into two large databases, PubMed/MEDLINE for journal articles and related documents, and LOCATORplus/NLM Catalog for books and related documents.

Citations from the *Bibliography of Bioethics* are available on the World Wide Web via the ETHXWeb and GenETHX databases, maintained by NRCBL. Access to these databases, along with searching information, is available through the Web gateway of the Kennedy Institute of Ethics at <http://bioethics.georgetown.edu>. In addition, a comprehensive NRCBL publication provides advice for database searchers: *Bioethics Searcher's Guide to Online Information Resources*. (See "Distribution" paragraph below for ordering information.)

## BIBLIOGRAPHY OF BIOETHICS

### Acknowledgments

It is a pleasure to acknowledge the assistance of several people and organizations who played significant roles in the production of this thirty-fifth volume of the *Bibliography of Bioethics*. Although this publication is not a direct product of federal funding, it depends upon critical support from the National Library of Medicine and the National Human Genome Research Institute, both at the National Institutes of Health. We wish to thank, in particular, our NLM Project Officers, Sara Tybaert, Martha Cohn, and Susan Von Braunsberg; our NLM Contracting Officer, Alex Navas; and Joy Boyer, Program Director, The Ethical, Legal, and Social Implications Program, National Human Genome Research Institute, for their interest and support. Other support is provided by the National Endowment for the Humanities, the Anderson Partnership, Max M. and Marjorie B. Kampelman, and many publishers and individuals who contributed copies of books and journal articles to NRCBL.

Patricia Milmo McCarrick, former reference librarian at NRCBL, continues as a library volunteer. Several Georgetown University students carried out document acquisition and data entry task: Rachel Cox, Rebecca Kruser, Timothy Oginio and Sarah Stodder.

### Distribution of the *Bibliography of Bioethics* and Related Publications

Inquiries about purchasing Volumes 10-35 of the *Bibliography* or the current edition of *Bioethics Searcher's Guide to Online Information Resources* should be directed to Library Publications, Kennedy Institute of Ethics, Georgetown University, Box 571212, Washington, DC 20057-1212, telephone 202-687-3885 or 888-BIO-ETHX (outside the Washington, DC metropolitan area); fax 202-687-8089, e-mail: [bioethics@georgetown.edu](mailto:bioethics@georgetown.edu).

### International Bioethics Exchange Project (IBEP)

IBEP, a project of the Kennedy Institute of Ethics, promotes research and education in bioethics in the developing world by donating multiple volumes of the *Bibliography* to libraries abroad in order to encourage the development of bioethics reference resources in those countries. In turn, IBEP is eager to collect documents about bioethics from the exchange participants. Any books, policy statements, periodicals and other materials about bioethical issues in the participant countries that are donated to IBEP are added to the NRCBL collection and considered for inclusion in the *Bibliography*. This project relies upon the support of donors to underwrite the transport of the volumes to the developing country library.

To date libraries in the following countries have become participants in the project: Argentina, Belarus, Brazil, Burkina Faso, Cameroon, China, Columbia, Congo (Republic of the), Costa Rica, Croatia, Eritrea, Gabon, Ghana, Grenada, Guinea (Republic of), Israel, Jamaica, Kenya, Korea (South), Liberia, Lithuania, Madagascar, Mauritius, Mexico, Nigeria, Papua New Guinea, Philippines, Poland, Portugal, Romania, Rwanda, Saint Lucia, Sierra Leone, Slovakia, Slovenia, South Africa, Sri Lanka, Sudan, Thailand, Trinidad and Tobago, Togo, Turkey, Uzbekistan, Venezuela, Yemen, and Zambia.

Contributions in support of an IBEP library or donations of bioethics books, reprints, audiovisual materials, and other documents should be sent to Lucinda Fitch Huttlinger, Acquisitions Librarian, Kennedy Institute of Ethics, Georgetown University, Box 571212, Washington, DC 20057-1212; Telephone: +202-687-6433; Toll-free telephone: 1-888-BIO-ETHX (U.S. and Canada); FAX +202-687-8089; e-mail: [bioethics@georgetown.edu](mailto:bioethics@georgetown.edu). All donations are reviewed for inclusion in the NRCBL collection as well as for this *Bibliography*.

The staff welcomes suggestions for the improvement of future volumes of the *Bibliography of Bioethics*. Please send all comments to:

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