International Research Ethics

Finding what you need – Access to information resources

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Indiana University Center for Bioethics

Teaching Skills in International Research Ethics Workshop ("TaSkR")
Indianapolis, Indiana. 21 April 2009.
Resources for international research ethics education?

What do you use?  –  What do you need?
International Research Ethics:
Finding what you need

1. Search Strategies: a refresher
2. Databases and Search Engines
3. On the Web: additional resources
4. Access?
Search Strategies: a refresher

1. Estimate depth of information need
2. Build a question
3. Search and (re)search
4. Know when to quit – “enough is enough”
Estimate depth of information need

• Keep your goal in mind
  – Responding to a case study?
  – Writing a focused article?
  – Conducting an exhaustive, systematic review?
  – Preparing a lecture?
  – Selecting readings for a class?

• Don’t let the search grow legs
Build a question

• Why?
  – Search engines, databases, and librarians are not mind readers.

• How?
  – Who, What, Where, When
The “well-built” clinical question

P I C O

• **Patient, population, problem**
  – What are the characteristics of the patient or population?

• **Intervention or exposure**
  – What do you want to do with this patient (e.g. treat, diagnose, observe)?

• **Comparison** (optional)
  – What is the alternative to the intervention (e.g. placebo, different drug, surgery)?

• **Outcome**
  – What are the relevant outcomes (e.g. morbidity, death, complications)?

The “well-built” ethics question?

P H R E [D]

• Population
  – Who? (age, gender, ethnicity, occupation, etc.) Where? (North America, Kenya, developing countries, etc.) When?
• Health condition
  – What? (obesity, tooth decay, clean water)
• Research method or field
• Ethics concern or topic
  – What?
• [Document type]
PHRED: Ethics concern or topic

Research ethics AND Internationality

• **Guidelines**
  • Codes of ethics
  • Government regulation
  • Public policy
  • Policy making

• **Ethical theory**
  • Autonomy
  • Beneficence
  • Justice
  • Paternalism
  • Virtues

• **Culture**
  • Cross-cultural comparison
  • Cultural diversity
  • Cultural pluralism
  • Social values

• **Misconduct**
  • Conflict of interest
  • Fraud
  • Professional misconduct
  • Scientific misconduct

• **Ethical review**
  • Ethics committees
  • Research ethics committees

Many of these keywords were selected from the NRCBL Bioethics Thesaurus: [http://bioethics.georgetown.edu/databases/bt/](http://bioethics.georgetown.edu/databases/bt/)
More PHRE[D]: Ethics concern or topic

• Researcher-Subject Relations
  • Access to information
    – Confidentiality
    – Duty to recontact
    – Duty to warn
    – Privacy
    – Truth disclosure
  • Informed consent
    – Assent
    – Community consent
    – Consent forms
    – Parental consent
    – Presumed consent
    – Third-party consent
  • Trust

• Social justice
  • Commodification
  • Resource allocation
  • Social responsibility

Many of these keywords were selected from the NRCBL Bioethics Thesaurus: http://bioethics.georgetown.edu/databases/bt/
Databases and search engines
Finding books, video and other items

• Your local library … or:

  – National Library of Medicine (NLM) -
    http://www.nlm.nih.gov/

  – National Reference Center for Bioethics Literature (NRCBL) -
    http://bioethics.georgetown.edu/nrc/
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<td>3</td>
<td>Bioethics and the prevention of biological warfare / Rita R. Colwell and Raymond A. Zilinskas.</td>
<td></td>
<td>2000</td>
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</tbody>
</table>
1: Dickert, Neal; National Institutes of Health (U.S.)
When should researchers provide clinical care to subjects?
[Bethesda, Md : National Institutes of Health, 2008]
NLM ID: 101458722 [Remote electronic resource, Videorecording]

2: Shah, Seema; National Institutes of Health (U.S.)
Ethical and regulatory aspects of clinical research. Session 7, Ethical issues in international research 2008
[Bethesda, Md : National Institutes of Health, 2008]
NLM ID: 101490629 [Remote electronic resource, Videorecording]

Ethical and regulatory aspects of clinical research. Ethical issues in international research
[Bethesda, Md : National Institutes of Health, 2007]
NLM ID: 101330967 [Remote electronic resource, Videorecording]
Reduced results from 93 to 9 items
ETHXWeb

Journal articles, book chapters, bills, laws, court decisions, reports, books, audiovisuals, and news articles relating to bioethics and professional ethics.

Basic Search | Advanced Search | Boolean Search | Search Tips

Use the plus sign, +, as the wildcard/truncation symbol.

Search Query:

Example: (privacy or confidentiality) and 15.3[cl]

Browse Database Fields List
NRCLBL Classification Scheme

Full text available on-line:  □

Publication Date Range:  All Years  □
NRCBL ETHXWeb

("developing countries" or "international aspects") and ("research ethics") and (bc[pt] or m[pt] or b[pt]) = 22 book chapters, monographs, books

Search Detail:
Result=1
Documents: 1 - 20 of 22

Click on highlighted title to display abstract or table of contents.

☐ Document 1
Steinbook, Bonnie; Arras, John D.; and London, Alex John, [eds.]
ETHICAL ISSUES IN MODERN MEDICINE: CONTEMPORARY READINGS IN BIOETHICS
Seventh edition
2.1; 2.3; ry
Location: RT24 E758 2009
Shelved at: library

☐ Document 2
National Research Council (United States). Human Embryonic Stem Cell Research Advisory Committee [and] Institute of Medicine (United States). Board on Health Sciences Policy
2008 AMENDMENTS TO THE NATIONAL ACADEMIES' GUIDELINES FOR HUMAN EMBRYONIC STEM CELL RESEARCH
Also available on the Web at: http://www.nap.edu
18.7, 2.4, 15.1, 18.2, 18.5.4, 19.5, 22.2
Link to full text provider
Location: QH442.2.N38 2008
**NRCBL Bibliographic Services**

*National Reference Center for Bioethics Literature*
*Kennedy Institute of Ethics*

**SEARCH REQUEST**

Please fill out this form to request a search. The * fields are required. We are unable to respond to your request without this information.

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**Email Address**

Search results will be emailed to you at this address

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<td>Name of College, University, or other Institution</td>
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Databases and search engines
Finding books, videos and other items

Google Books
http://books.google.com/

WorldCat
http://www.worldcat.org/

nearest library with item:
Brebeuf Preparatory School
Indianapolis, IN 46268
(8 Miles)
When science offers salvation, patient advocacy and research ethics - Page 114
by Rebecca Dresser - Medical - 2001 - 216 pages
International groups also see community oversight as essential to research ethics review. Most influential in this area are guidelines issued by the Council ...
Limited preview - About this book - Add to my shared library - More editions

Ethics and research with children; a case-based approach - Page 241
by Eric Kodish - Psychology - 2005 - 361 pages
13 Testing Drugs in Developing Countries. Pediatric Research Ethics in an International Context Michelle Eder CASE DESCRIPTION In 2001, a pharmaceutical ...
Limited preview - About this book - Add to my shared library - More editions

Exploitation and Developing Countries: The Ethics of Clinical Research - Page 21
by Jennifer Hawkins, Ezekiel J. Emanuel - Medical - 2003 - 327 pages
Research Ethics, Developing Countries, and Exploitation: A Primer JENNIFER S. ... relevant for the discussions of international research that follow. ...
Limited preview - About this book - Add to my shared library

Ethical Challenges in Study Design and Informed Consent for Health Research - Page 10
In recent years, there have been increasing efforts to address ethical issues in international research through educational programmes and policy and ...
Full view - About this book - Add to my shared library
Google Books: Advanced Search

**Advanced Book Search**

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<th>Find results</th>
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<th>developing countries</th>
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**Search:**
- All books
- Limited preview and full view
- Full view only

**Content:**
- All content
- Books
- Magazines

**Language**
Return pages written in

**Title**
Return books with the title
- e.g. Books and Culture

**Author**
Return books written by
- e.g. Hamilton Mable or "Hamilton Wright Mable"

**Publisher**
Return books published by
- e.g. O'Raily

**Subject**
Return books on subject
- "bioethics"
- e.g. Medieval History or "Medieval History"

**Publication Date**
- Return content published anytime
- Return content published between
- e.g. 1999 and 2000, or Jan 1999 and Dec 2000

**ISBN**
Return books with the ISBN
- e.g. 060830314

**ISSN**
Return serials with the ISSN
When is clinical research in developing countries exploitation? Exploitation is a concept in ordinary moral thought that has not often been analyzed outside the Marxist tradition. Yet it is commonly used to describe interactions that seem morally suspect in some way. A case in point is clinical research sponsored by developed countries and carried out in developing countries, with participants who are poor and sick, and lack education. Such individuals seem vulnerable to abuse. But does this, by itself, make such research exploitative? Exploitation and Developing Countries is an attempt by philosophers and bioethicists to reflect on the meaning of exploitation, to ask whether and when clinical research in developing countries counts as exploitative, and to consider what can be done to minimize the possibility of exploitation in such circumstances. These reflections should interest clinical researchers, since locating the line between appropriate and inappropriate use of subjects—the line between exploitation and fair use—is the central question at the heart of research ethics. Reflection on this rich and important moral concept should also interest normative moral philosophers of a non-Marxist bent. In addition to the editors, the contributors are Richard J. Arneson, Alica L. Caro, Margaret Olivia Little, Thomas Fogge, Andrew W. Siegel, and Alan Wertheimer.
WorldCat: Find in a library

Services from INDIANA UNIV, PURDUE UNIV, IND for this item: Find It @ IUPUI! No IU Copy? Request Via ILLiad | Check for Electronic Resources | Full-text available from Clarion Library | Search IUCAT | INCat-Indiana University Catalog | CCIL FirstSearch

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   Bloomington, IN 47405 United States
   47 miles

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   Mishawaka, IN 46545 United States
   131 miles

4. University of Notre Dame
   Notre Dame, IN 46556 United States
   132 miles

5. University of Chicago
   Chicago, IL 60637 United States
   157 miles
WorldCat

“research ethics” AND “international research”

1. The bioethics reader: editors’ choice
   - By Ruth F Chadwick, et al.
   - Book
   - Language: English
   - Publisher: Maiden, MA; Oxford: Blackwell Pub., 2007.

2. International research ethics: a needs assessment of research ethics capacity at Moi University and Indiana University
   - By Eric Mark Meslin; Indiana University School of Medicine; Moi University. Faculty of Health Sciences; Indiana University. Center for Bioethics; et al.
   - Book
   - Language: English
   - Publisher: Indianapolis: Indiana University Center for Bioethics, [2005]

3. Language barriers and qualitative nursing research: Methodological considerations
   - By Squires A.
   - Article
   - Language: English
Databases and search engines
Finding articles and other items in journals

• Use your library’s databases
  – A few useful databases accessible at IUPUI:
    • Global Issues In Context
    • Humanities International Index
    • JSTOR
    • MEDLINE
    • Philosopher's Index
    • PsycINFO
    • Sociological Abstracts
    • Web of Science (ISI)

• Or …
Databases and search engines

Finding articles and other items in journals – free tools

  – Free to use, systematic searches
  – Limits to free full text
  – Limits to bioethics: add bioethics[sb] to your search

• Google Scholar - http://scholar.google.com/
  – Broad coverage of the literature
  – Links to full text when available
Building a PubMed MEDLINE Search

• What are the best ways to teach research ethics?

• What are the [best] ways to teach research ethics?

• Possible search terms?
  – Teaching methods
  – Pedagogy
  – Research ethics
  – Responsible conduct of research
1: Teaching
   The educational process of instructing
2: education [Subheading]
   Used for education, training programs, and courses in various fields and disciplines, and for training groups of persons.
   Year introduced: 1967
PubMed MeSH: “teaching”

1. **Teaching**

   The educational process of instructing.

   **Subheadings:** This list includes those paired at least once with this heading in MEDLINE and may not reflect current rules for allowable combinations.

   - classification  
   - economics  
   - education  
   - ethics 
   - history  
   - legislation and jurisprudence 
   - manpower 
   - methods 
   - organization or administration 
   - psychology 
   - standards 
   - statistics and numerical data 
   - supply and distribution 
   - trends

   - Restrict Search to Major Topic headings only
   - Do Not Explode this term (i.e., do not include MeSH terms found below this term in the MeSH tree).

   **Entry Terms:**
   - Personal Educational
PubMed: Combine Terms or Searches with OR and/or AND

- If making selections (e.g., Subheadings, etc.), use the Send to Search Box feature to see PubMed records with those specifications.
- Select PubMed under the Links menu to retrieve all records for the MeSH Term.
- Select NLM MeSH Browser under the Links menu for additional information.

1: Ethics, Research

The moral obligations governing the conduct of research. Used for discussions of research ethics as a general topic.
Year introduced: 2003

Subheadings: This list includes those paired at least once with this heading in MEDLINE and may not reflect current rules for allowable combinations.

- education
- history

- Restrict Search to Major Topic headings only.
- Do Not Explode this term (i.e., do not include MeSH terms found below this term in the MeSH tree)

...
What are the best ways to teach research ethics?

- “teaching/methods”[Mesh] AND “ethics, research/education”[Mesh]) = 12
  - {18,070 AND 117}

- ("teaching methods" OR "teaching/methods"[Mesh]) AND (("research ethics" AND education) OR "Ethics, Research/education"[Mesh]) = 19
  - {18870 AND 598}

- (pedagogy OR "teaching methods" OR "teaching"[mh] OR "teaching/methods"[mh] OR "models, educational"[mh] OR "problem-based learning"[mh]) AND ("research ethics“ OR ("responsible conduct" AND ("research"[mh] OR "research"))) OR "ethics, research"[mh]) = 56

http://is.gd/sRQE
PubMed: Useful Limits
Google Scholar

• Free!
• Broader coverage; sloppier results
• "research ethics" (pedagogy OR "teaching methods") (medicine OR "medical research" OR "biomedical research" OR "clinical trials" OR "human experimentation") = 1,370 results
Google Scholar: Research ethics and teaching methods

Results 1 - 10 of about 1,370 for "research ethics" (pedagogy OR "teaching methods") (medicine OR "medical research")

[BOOK] Research ethics. Cases and materials
RL Peisnar - 1995 - books.google.com
... PART I Theory and Pedagogy ... General issues in Teaching Research Ethics Kenneth D. Pimple 1 ... in everyday life, in government, journalism, medicine, education ...
Cited by 36 - Related articles - Web Search - Library Search - BL Direct - All 3 versions

Clinical ethics revisited - Find it @ IUPUI
PA Singer, ED Pellegrino, M Siegler - BMC Medical Ethics, 2001 - biomedcentral.com
... Different clinical ethics teaching methods have been used ... in bioethics, including biotechnology, research ethics, end-of ... Annals of Internal Medicine 2000, 133:59 ...
Cited by 47 - Related articles - Cached - Web Search - All 11 versions

Curricular approaches to research ethics training for psychiatric investigators - Find it @ IUPUI
DT Chen - Psychopharmacology, 2003 - Springer
... and evaluate creative models for teaching psychiatric research ethics ... patient care/to practice medicine responsibly To ... for freedom: the paradox of pedagogy ...
Cited by 15 - Related articles - Web Search - All 3 versions

Development of a teaching program in clinical medical ethics at the University of Chicago - Find it @ IUPUI
RM Walker, LW LANE, M SIEGEL - ethics
Cited by 14 - Related articles - Web Search - All 3 versions

http://is.gd/sRQ1
# Google Scholar: Advanced Search

## Find articles
- with all of the words
- with the **exact phrase**
- with at least one of the words
- without the words
- where my words occur

## Author
Return articles written by

## Publication
Return articles published in

## Date
Return articles published between

## Subject Areas
- Return articles in all subject areas.
- Return only articles in the following subject areas:
  - Biology, Life Sciences, and Environmental Science
  - Business, Administration, Finance, and Economics
  - Chemistry and Materials Science
  - Engineering, Computer Science, and Mathematics
  - Medicine, Pharmacology, and Veterinary Science
  - Physics, Astronomy, and Planetary Science
  - Social Sciences, Arts, and Humanities
On the Web: Additional Resources

http://www.bioethics.iu.edu/ireguide.asp

International Research Ethics: Subject Guide

This subject guide supports researchers and students interested in the ethical issues of multinational research. These issues include: the obligations of wealthy nations to the countries and communities in which they conduct research, the impact of cultural differences on the interpretation and implementation of ethics oversight and guidelines, discrepancies between national regulations, and other topics.

Although the guide emphasizes resources for Indiana University-Moi University Academic Research Ethics Partnership (IU-Moi AREP) and, therefore, gives special attention to issues in Kenya and other countries in east Africa, many of the resources described here are applicable to the broader study of ethical issues in biomedical research.

Because the IU-Moi AREP (like many international research studies) spans two academic institutions and two continents, this guide points (when possible) to resources that are freely available online.

If you have comments or suggestions about this guide, please contact: Jero Odeg

Databases

BELIT - Bioethics Literature Database
A bibliographic database maintained by the German Reference Centre for Ethics in the Life Sciences (DRZE), BELIT provides access to about 350,000 records. Coverage includes holdings in German, French and American databases. To
On the Web: Additional Resources

http://www.citeulike.org/user/cntbioet/tag/taskr

cntbioet's taskr [50 articles]
Recent papers added to cntbioet's library classified by the tag taskr. You can also see everyone's taskr.

Hide details

Teaching Ethics to Scientists and Engineers: Moral Agents and Moral Problems - Online Ethics Home
by C. Whitbeck
posted to taskr ire engineering education by cntbioet on 2009-04-20 15:24:34 as ★★

Problems and Cases: New Directions in Ethics 1980-1996 - Online Ethics Home
by C. Whitbeck
posted to taskr ire education cases by cntbioet on 2009-04-20 15:22:50 as ★★

Case-based Approaches to Professional Ethics: a systematic comparison of students' and ethicists' moral reasoning
by M. Keefer, R.J. Toulmin
posted to taskr ire education by cntbioet on 2009-04-20 15:05:29 as ★★

Disconnections Between Teacher Expectations and Student Confidence in Bioethics
by Rikkik Lelivelpa, Laura Price, Jeremy Peterson
posted to taskr ire education by cntbioet on 2009-04-20 15:00:08 as ★★

How to best teach bioethics: report from a workshop March 2003 organised by the Nordic Committee on Bioethics and NorFA.
by A. Olsen, H. von Trier
posted to taskr ire education by cntbioet on 2009-04-20 14:56:55 as ★★

The absent professor: why we don't teach research ethics and what to do about it.
by A. Eisen, M. Perry
posted to taskr research-ethics ire education by cntbioet on 2009-04-20 14:52:22 as ★★

Medical ethics education: where are we? Where should we be going? A review.

cntbioet's tags
All tags in cntbioet's library
Filter:
On the Web: Selected resources

- **Bioethics Resources on the Web: International Research Ethics** – NIH Web guide (some dead links) http://bioethics.od.nih.gov/internationalresthetics.html
- **Globalethics.net** – digital library, search engine, professional networking http://www.globethics.net
- **Online Ethics Center** – for engineering, but good resources on ethics education http://www.onlineethics.org/
- **Poynter Center** - Teaching Research Ethics – resources for ethics education http://poynter.indiana.edu/tre/
Access?


- **Sugarman** J. Ethical oversight of multinational collaborative research: lessons from Africa for building capacity and for policy. *Research Ethics Review* 2007;3: 84-86. [print only and not at IU]
Access?

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Journal of International Biotechnology Law - 4(2):Pages 59–74; Challenging a Well Established Consent Norm?: One Time Consent for Biobank Research, Electronic, Individual (access for 24 hours for US $40.00)

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The cost of scholarly journals has increased at 10% per year for the last three decades. This is over six times the rate of general inflation and over two and a half times the rate of increase of the cost of health care. Between 1975 and 2005 the average cost of journals in chemistry and physics rose from $76.84 to $1,879.56.

Access?


Nearest library copy to Indianapolis: University of Cincinnati, Medical Center; Cincinnati, OH - **99 miles or 159 KM**

Only known library copy in Africa: University of Kwazulu-Natal, Pietermaritzburg - **2,112 miles or 3,400 KM from Eldoret**
Authors, contribute to accessible archives

Bioethics Digital Library
https://idea.iupui.edu/dspace/handle/1805/6

Globethics.net
http://www.globethics.net/
What do we need for international research ethics education?
Needs?

• What are the [minimum] library and information resources required for an “international research ethics” education?
  – Intensive course vs M.A.?
  – In North America?
  – In East Africa?
Resources for International Research Ethics Education

• What do we need?
• What can be done now to meet these needs?
• What could be done with effort and money?
Comments? Questions?

Jere Odell
jodell@iupui.edu
www.bioethics.iu.edu